REPORT OF THE CANCER SERVICES IMPLEMENTATION COMMITTEE

Alan R. Hudson, OC
Chair

DECEMBER 2001

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December 2001

The Honourable Tony Clement
Minister of Health and Long-Term Care
Government of Ontario
Toronto, Ontario

Dear Mr. Clement:

I am pleased to submit the *Report of the Cancer Services Implementation Committee* on behalf of all of the members of the Committee.

Every member that was approached to serve on the Committee accepted the invitation, and I commend their skill and conscientiousness to you. The Committee considered a broad range of information including the results of widespread consultations.

The programs of the Ministry of Health and Long-Term Care have evolved over the years, each building upon previous programs, structures and functions. This report recommends logical and doable next steps to improve the integration and coordination of cancer care in Ontario.

If the recommendations of the Committee are accepted, the first course of action will be to develop and implement an action plan that will realise the fulfilment of the recommendations of this report. Cultural changes in a variety of organisations that provide cancer services will be necessary if they are to lead and execute these plans.

I believe that the implementation of these recommendations will lead to a more effective cancer services system for the citizens of Ontario.

Yours sincerely,

Original Signed

Alan R. Hudson, OC
Chair

Original

Signatures of all Committee Members

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ACKNOWLEDGEMENTS

The members of the Cancer Services Implementation Committee willingly volunteered their time and expertise, attended meetings, read background material and debated the issues thoroughly. The commitment of these individuals is gratefully acknowledged.

The Committee heard from a number of expert presenters who not only educated the Committee on a wide range of cancer-related issues but also provided much food for thought. In addition, public consultations, invitational sessions, site visits to the regional cancer centres, and consultations with health care organisations and associations provided the Committee with invaluable insights from consumers, health care professionals, union leaders and administrators. Thanks are extended to all those who gave generously of their time and expertise.

Sandy Nuttall, Shannon Tyler and Elaine Bishop, staff of the Ministry of Health and Long-Term Care, provided administrative support to the Committee. Carole McKeogh of the Ministry's Legal Services Branch provided invaluable legal expertise. The support of these individuals was appreciated.

Joann Trypuc worked with the Committee, helped facilitate the discussion of issues and authored the report. Her contributions were invaluable and are gratefully acknowledged.

Finally, sincere thanks are extended for the financial support from the Ministry of Health and Long-Term Care and for the personal support from the Department of Surgery, University of Toronto over the course of this work.

Alan R. Hudson
Chair

EXECUTIVE SUMMARY

In July 2001, the Cancer Services Implementation Committee was struck in response to public concerns about waiting lists for radiation therapy and the ability of the current system to meet the growing need for cancer services of all kinds. The focus of the Committee was to recommend ways to improve the integration of cancer services at the local and regional levels, the quality of patient care, and the productivity and efficiency in the cancer service component of the Ontario health system. The Committee considered a broad range of information including the results of widespread consultations.

Cancer care in Ontario is becoming increasingly important. The proportion of disease and deaths from cancer is dramatically increasing, and there is a growing awareness of the broad continuum of cancer care. Currently, Ontario spends about $1.5 billion on cancer care with increasing pressures to invest more.

Over the course of its review, the Committee found that:

- Cancer care is fragmented and needs to be better co-ordinated.
- Information systems are fragmented and unable to support and monitor improvements in access, care and outcomes at the provincial, regional and local levels.
- A quality bar needs to be set and supported by standards to ensure that all patients receive the same quality care no matter where they live in the province.
- Funding approaches are inadequate to ensure appropriate cancer funding in hospitals (currently hospitals can allocate their budgets according to their individual priorities).
- Although a complex array of cancer services is provided by many individuals, most of whom also care for non-cancer patients, a comprehensive picture of who these individuals are, what they do, how much they do and what their outcomes are, does not exist. The cancer services system is characterised by many governors and managers who only oversee pieces of the system.

These factors all result in a cancer services system that lacks integration and coordination. The Committee made a number of recommendations that address this fundamental issue.

- After exploring a number of options, the Committee recommended that the role of Cancer Care Ontario (CCO), as principal advisor to the Minister of Health and Long-Term Care on *all* matters related to the cancer control system and cancer control services, should be strengthened. This includes health promotion and disease prevention, screening, primary care, diagnostics, treatment, rehabilitation, home/ community care, supportive and palliative care. CCO should focus on and be accountable for providing strategic direction for the cancer services system, developing standards and guidelines to support quality cancer care across the continuum, monitoring system performance, addressing problem areas, ensuring timely and equitable access to care, and ensuring the effective use of resources to support the full continuum of cancer services.
- CCO should establish Regional Cancer Advisory Bodies, made up of a broad range of stakeholders, to plan and oversee the integration of all regional cancer services.

Activities at the regional level will be pivotal for bringing cancer providers together, and improving the quality and integration of cancer services in the regions. These bodies should co-ordinate services at the regional level, be accountable to the CCO board, and provide reports to stakeholders including the public. The key focus of activity to develop integrated care should be at the regional level. Indeed, the regional bodies will make up the Cancer Care Ontario System.

- CCO's new and existing regional cancer centres should move towards greater integration of cancer services into one program with host hospitals. This includes a joint oncology program, single leadership for the integrated oncology program, joint support staff and an annual joint operating plan for the integrated program.
- CCO and other cancer system stakeholders should work with the Ministry of Health and Long-Term Care (Ministry) to develop and implement a cancer information strategy that will be the backbone for an integrated cancer services system. The strategy should address management and clinical information, an integrated patient record and a fully-linked comprehensive database that will support research. A focus on staging cancer patients consistently and developing uniform pathology reporting will strengthen the quality of, and access to, care.
- CCO should establish a Cancer Quality Council to monitor, assess and improve clinical and health system performance of all cancer services in Ontario. The Council will have strong positive impacts on quality of care by overseeing the development of evidence-based tools, monitoring their use and targeting performance improvements.
- The Ministry, on the advice of CCO and other stakeholders, should develop a comprehensive and consistent funding approach for cancer services in the province that includes an envelope of funds that are protected for cancer and allocated using volume, complexity and quality considerations. The envelope will gradually encompass the whole continuum of cancer services in the province as part of an integrated approach to care.
- CCO should continue to develop a provincial cancer human resources strategy to support the training, recruitment and retention of a sufficient number of professionals to provide cancer services. To ensure there is an adequate supply of human resources to provide the full range of cancer services, the Ministry must move quickly to create additional training positions in key areas.
- CCO should work with stakeholders to develop strategies to support the professional development of, and advance communication between, providers. This will improve timely access to care and result in more co-ordinated patient care.

The Committee recognises that cancer is one of a number of competing priorities for limited health care resources. Its recommendations attempt to make the most effective and efficient use of resources while focusing on the patient and the need to provide quality, integrated care. The Committee's recommendations also take into account the system's capacity for change, and are sensitive to the need for appropriate conditions and timing to support and sustain system change.

The Committee believes that its recommendations are a key transition step that will facilitate the move to the full integration of cancer services in the province and position the system to meet the challenges of the future.

PART ONE: INTRODUCTION

1. BACKGROUND

THE CANCER SERVICES REVIEW

In the spring of 2001, the Minister of Health and Long-Term Care, Tony Clement, asked Dr. Alan R. Hudson to advise him on modifications to improve the current system of cancer services in Ontario. The Minister was responding to public concerns about waiting lists for radiation therapy, and the ability of the current system to meet the growing need for cancer services of all kinds. Preliminary discussions were held between the Minister, Dr. Hudson and Mr. Peter Crossgrove, Chair of Cancer Care Ontario. It was agreed that an independent committee should be struck to examine the issues and provide advice to the Minister by the end of December 2001.

On June 5, 2001, the Minister appointed Dr. Hudson as Chair of the Cancer Services Implementation Committee (Appendix A).

The Committee was guided by the following terms of reference:

- The essential goal of the Committee is to make recommendations to improve integration of cancer services at the local level in the province of Ontario. These recommendations should result in the improved quality of patient care and improved productivity and efficiency in the cancer service component of the Ontario health system.

- The Committee should examine the current situation and suggest modifications or alternative models. It is anticipated that the committee will develop principles in support of integration of cancer services at the local/regional level. The site of governance and management authority, responsibility and accountability should be clearly demarcated in the model(s) recommended by the committee.

See Appendix B for the full terms of reference.

When the Committee began its work, a web site was developed that reported on the Committee's activities and progress.

THE COMMITTEE

The Committee was made up of individuals reflecting a wide range of expertise in the cancer services and health care systems. Committee members included health care providers and executives, board trustees, consumers, academics, researchers, health care consultants and senior government staff (Appendix C). These individuals were chosen

for their expertise and judgement, and not as representatives of particular constituencies or organisations.

The Committee was supported by an independent consultant, and staff of the Hospitals Branch of the Ministry of Health and Long-Term Care. The Committee held its first meeting on July 12, 2001 and met 12 times over the course of its work.

STRATEGIES USED

Three strategies were used to support the work of the Committee – presentations to the Committee, consultations, and a literature and data review. The Committee used the results of these strategies to inform its discussions and develop its recommendations (see Appendix D).

Presentations to the Committee

The Committee heard from external individuals who presented information on issues related to the cancer services system. Individual Committee members also made presentations on key topics as well as spoke to local issues.

Consultations

Consultations were conducted with a wide range of stakeholders. These consultations included:

- The Chair of the Committee made site visits to the eight regional cancer centres in the province as well as the centres under development. At each site, the Chair met with the CEO of the centre and others to share information and discuss issues.
- Consultations (public and invitational) were held in four locations – Kingston, Sudbury, Thunder Bay and Toronto – to seek advice on the integration of cancer services and increased efficiencies at the local level.
- The Chair consulted individually with a number of organisations, associations and groups on issues related to cancer services in the province. These meetings were used to inform board members or senior officials of the work of the Committee and to seek informal feedback.

Literature and Data Review

A wide range of literature related to cancer services in Ontario and other jurisdictions was reviewed. In addition, data were obtained from Cancer Care Ontario, Princess Margaret Hospital (University Health Network) and the Institute for Clinical Evaluative Sciences. This information provided an overview of the Ontario system as well as helped identify potential directions for the future.

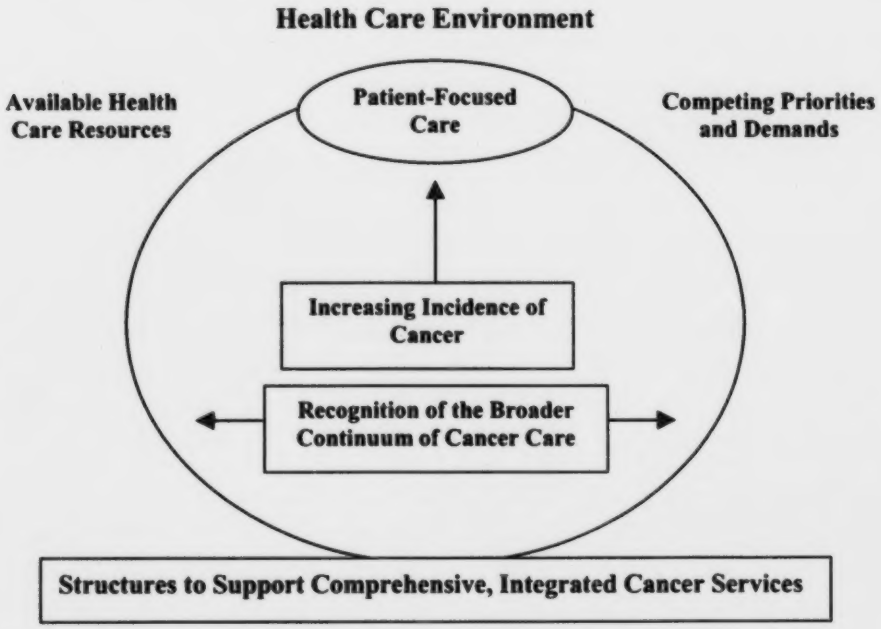
FRAMING THE WORK OF THE COMMITTEE

The Committee discussed six areas that helped to frame its discussions:

- The definition and nature of cancer;
- The increasing need for cancer care;
- A focus on the patient;
- The environmental context;
- The Committee's vision for the cancer services system and criteria to guide its deliberations; and
- Structures to support comprehensive, integrated cancer services.

Figure 1 depicts the increasing need for cancer care, a focus on the patient, and the environmental context considered by the Committee.

Figure 1: Framing the Work of the Committee


Health Care Environment
Available Health Care Resources
Patient-Focused Care
Competing Priorities and Demands
Increasing Incidence of Cancer
Recognition of the Broader Continuum of Cancer Care
Structures to Support Comprehensive, Integrated Cancer Services

The Definition and Nature of Cancer

Cancer is a group of diseases that is characterised by an uncontrolled division and growth of cells of various tissues of the human body. Initially, this abnormal cellular behaviour may remain confined but subsequently it may spread to the tissues surrounding the abnormality. Cancer cells may break away and spread to other parts of the body by the

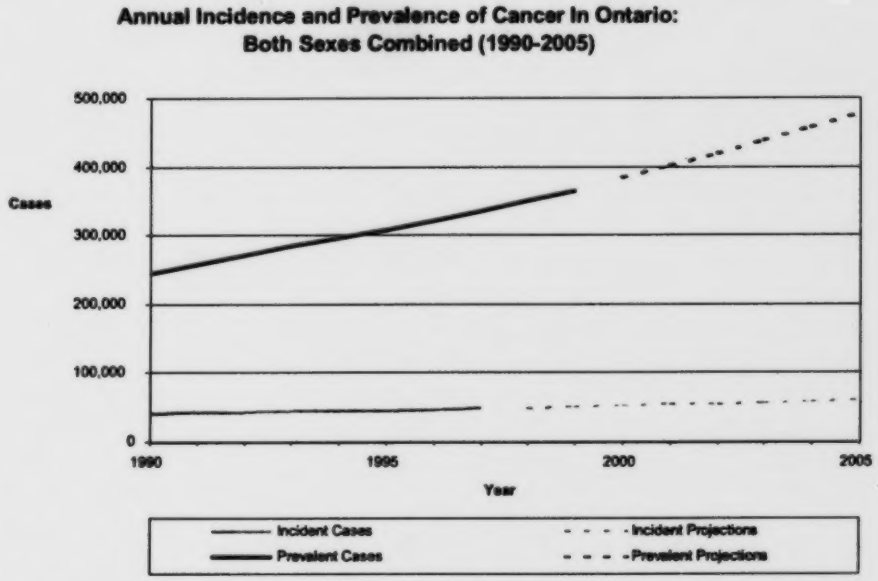
lymphatic or blood pathways. These cancer cells, of the same kind as the original tumour, may start growing at sites distant from the original malignant tumour. The diagnosis of cancer is made by reviewing information derived from the patient's history, physical examination and special tests. Two crucial tests include the examination of the tumour tissue and the imaging of the patient's body. These help determine the exact nature of the specific tumour and the degree of spread that has occurred.

In the majority of cases, the illness is of a chronic nature with acute episodes. These episodes may be due to the underlying disease, an exacerbation or recurrence of the disease, or complications of treatment. The patient may also suffer from a variety of concurrent illnesses, not specifically related to cancer.

The Increasing Need for Cancer Care

The impact of cancer on the health care system is affected by the increasing incidence of cancer (those diagnosed with cancer in a given year) and the rapidly growing prevalence of cancer (those living with the disease). The incidence of cancer in Ontario is increasing 3% annually,[1] and is projected to increase 11.7% from 2001 to 2005 (53,430 people in 2001 to 59,671 in 2005). The prevalence of cancer is projected to increase 18% over the same time period. In 2005, more than 475,000 Ontarians will be living with cancer (Figure 2).

Figure 2: Annual Incidence and Prevalence of Cancer in Ontario



[1] Ontario Cancer Registry, 1998. Data provided by Ian Brunskill, Cancer Care Ontario.

Although the age-standardized mortality rates for cancer *as a whole* have remained relatively constant,[2] the combination of stable mortality rates and decreases in mortality from other diseases such as heart disease and stroke, means that the proportion of disease and deaths from cancer has been increasing. While it is positive that new and complex therapies are enabling people with cancer to live longer, this is placing increasing pressure on services for cancer patients in Ontario.

In addition to the increasing incidence and prevalence of cancer, there is growing recognition of the importance of the broad continuum of care. This includes health promotion and disease prevention, screening, primary care, diagnostics, treatment, rehabilitation, home/community care, supportive and palliative care. The increasing awareness of the importance of each of these components and the need to coordinate them for "seamless" cancer care for a particular patient, are resulting in greater demands for cancer resources and new ways of providing care.

A Focus on the Patient [3]

Cancer services are provided by many care providers who represent a wide variety of professional groups. The patient and his or her family are the only constants in the continuum of care that may exist over months or years. Patient-focused care emphasizes the patient participating in his or her care. It also emphasizes individual providers and organisations committed to practices that put the patient before the provider and organisational priorities.

Typically, the Ontario health service industry has been modeled to suit the needs of providers. As in any service industry, it is the opinion of the purchaser or consumer, that should be of paramount importance. The opinion of those at risk – all of us, patients suffering from cancer and those who were fortunate enough to survive this disease – should constantly be sought, analysed and publicised.

Although patient-focused care may characterize each individual patient-provider interaction, the challenge is to ensure that patient-focused care is an integral part of the full continuum of care over time and the linkages between the components. Various professionals must coordinate their activities and share patient information with each other and with the patient so that care is coordinated and the patient has a seamless care experience. This focus on the patient is compatible with the essential goal of the committee – to improve integration of cancer services at the local level.

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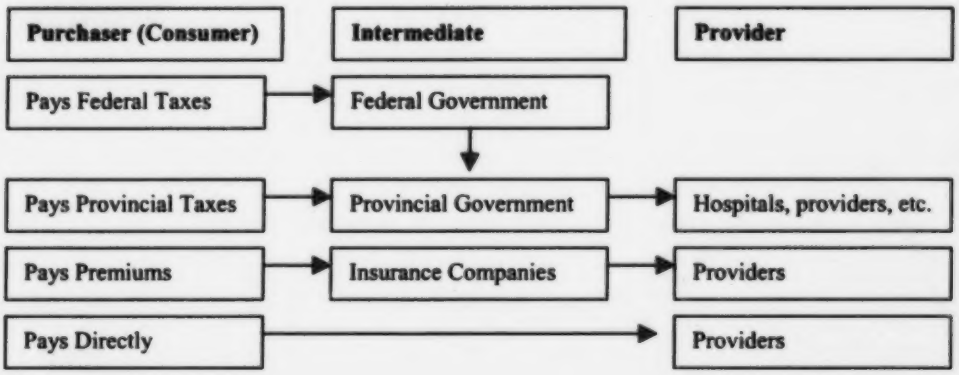
[2] The constant rates are from 1981 to 1995. Cancer is an aggregate of diseases. The mortality rate of some cancers has declined whereas rates have remained stable for other cancers. *Report on the Health Status of Ontario Residents*, Chapter 6: "Chronic Disease". Pp. 48-77.

[3] Different terms are used in health care such as patient, client, consumer and resident. This report uses the term "patient" to encompass all of these terms and for ease of reading.

The Environmental Context

Currently, the provincial government spends $23.7 billion on health care in Ontario. The provincial government receives revenues from its tax system, and by provincial/federal agreement from the federal government (Figure 3).

Figure 3: Health Care Funding Flow



According to the Canadian Institute for Health Information, Canadians will spend $102.5 billion on health care in 2001. Of this, public sector spending is forecasted to reach $74.5 billion (73%) and private sector spending (health insurance premium and out-of-pocket payments) is forecasted to reach $28 billion (27%).[4]

Cancer care is one of the major health programs supported by the provincial government. Although some payments are cancer-specific such as radiation therapy, the majority of funds support staff and equipment that are used to care for a variety of different patients in addition to those with cancer (e.g., emergency departments are used by cancer patients and patients with other disorders). As well, cancer patients who access cancer-specific services (e.g., a leukemia clinic) may also access services in other major programs (e.g., cardiac, respiratory, imaging and pathology).

The Committee recognises that cancer is one of a number of competing priorities for limited health care resources. These priorities are not necessarily mutually exclusive since a cancer patient may have other conditions that require attention. Some of the most prevalent clinical conditions that are also placing demands on health care resources include:

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[4] Canadian Institute for Health Information, *National Health Expenditure Trends, 1975-2001*, December 2001.

- Cardiac: Although death rates from heart disease have been declining steadily in Ontario since the 1960s,[5] the number of deaths from heart disease is expected to almost double by 2018 due to population growth and aging (excluding further improvement in mortality rates). Morbidity due to heart disease is also increasing – close to half of heart attack survivors continue to experience heart-related problems including ischemia, chest pain, a restricted lifestyle and a high risk of a repeat heart attack.[6]

- Stroke: Although the total age-standardized mortality rates for stroke decreased by 34% between 1981 and 1995 (most of this decrease occurred in the 1980s),[7] age-specific mortality rates for stroke increase dramatically for those over age 65. The number of deaths due to stroke is expected to increase with the aging population. It is estimated that there are 15,000 to 20,000 strokes a year in Ontario,[8] with the number of strokes expected to increase 9% over the next ten years in Ontario.[9]

- End-Stage Renal Disease: The prevalence and incidence of end-stage renal disease are increasing at a high rate. In the U.S., these figures are approximately twice what they were 10 years ago.[10]

It is recognised that planning for cancer services cannot be done in isolation of planning for all health services in Ontario. The Committee's observations and recommendations bear in mind the principle that cancer care is part of the larger health system. The demand for cancer services will always comes up against the finite availability of funds and the competing priorities for these funds.

The issue of competing priorities has ethical and social implications that are eventually translated into Ministry policy decisions. There are many disease processes characterised by a chronic course, acute exacerbations, limitation of life expectancy and attendant high anxiety for patients, their families and their care providers. Cancer is an important member of this group. Who decides if more resources should flow to cancer patients than to patients suffering from hydrocephalus, AIDS, quadraplegia, end stage renal disease, diabetes or asthma? Who decides on the relative funding of cancer compared to other important disease groups that impose a highly significant burden on the patient, family and society, such as arthritis? These decisions are ethical and social, and not a medical responsibility. The government of Ontario and the Ministry have to interpret the political

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[5] Ben Chan and Wendy Young, "Burden of Cardiac Disease." In C. David Naylor and Pamela M. Slaughter (eds.) *Cardiac Health & Services in Ontario: An ICES Atlas*. Toronto: Institute for Clinical Evaluative Sciences, 1999. Pp. 1-13.

[6] Heart and Stroke Foundation of Canada, *Annual Report Card on Canadians' Health*, February 2001.

[7] *Report on the Health Status of Ontario Residents*, Chapter 6: "Chronic Disease." Pp. 48-77.

[8] Heart and Stroke Foundation of Ontario estimates as reported in the *Stroke Rehabilitation Consensus Panel Report: Submitted to the Heart and Stroke Foundation of Ontario*, May 2000.

[9] Estimates from the Institute for Clinical Evaluative Sciences, as reported in the Heart and Stroke Foundation of Ontario and the Ontario Ministry of Health and Long-Term Care, *Towards an Integrated Stroke Strategy for Ontario: Report of the Joint Stroke Strategy Working Group*, June 2000.

[10] Thomas H. Hostetter, "Editorial," *New England Journal of Medicine* Vol. 345 (12), September 20, 2001. Pp. 910-912.

will of voters. There is clearly a very strong message that cancer services need attention. Health Minister Clement has added his personal concerns to this message in calling for this Committee review.

Finally, the Committee's observations and recommendations take into account the system's capacity for change. The volunteer boards of many Ontario hospitals are still coping with the impact of hospital restructuring. As well, boards of hospitals and community agencies are struggling to fulfil their responsibility of balancing their budgets and providing quality patient care. As a result, the Committee concluded that its recommendations should strengthen the cancer system through evolutionary change in how services are structured. This decision is right for these times. With change, the appropriateness and success of the Committee's recommendations should be assessed and changes made accordingly.

The Committee's Vision for the Cancer Services System and Criteria to Guide its Deliberations

The Committee's vision for the cancer services system was:

> All Ontarians will have timely and equitable access to comprehensive and integrated quality cancer services.

The Committee identified six criteria that it used to guide its deliberations. The criteria reflected the broad aims that the Committee was trying to achieve for cancer services:

1. Quality care that supports the important role of patients/clients and their families as participants in that care, that meets the needs of these individuals, and upholds best practices.

2. Timely, equitable and appropriate access to comprehensive cancer services.

3. A system of integrated and coordinated services that supports a seamless care experience for the patient throughout the course of the disease.

4. Clear accountability for the planning, provision and auditing of quality care, timely access to appropriate services, effective outcomes and performance improvements.

5. Effective and efficient provision of services that makes the best use of human, financial, information and technological resources.

6. Conditions that attract and retain sufficient appropriately qualified care providers.

Structures to Support Comprehensive, Integrated Cancer Services

The structures that have supported cancer services in Ontario have evolved over time in response to changing needs. A key role of the Ontario Cancer Treatment and Research Foundation (OCTRF) – established in 1943 – was to control the delivery of radiation therapy in centralised facilities. In 1997, the organisation evolved into an operational service agency of the Ministry of Health and was renamed Cancer Care Ontario (CCO). CCO was established as the Minister's principal advisor on cancer care. It also assumed the operational responsibility of its predecessor to operate eight regional cancer centres providing radiation and systemic therapy services.

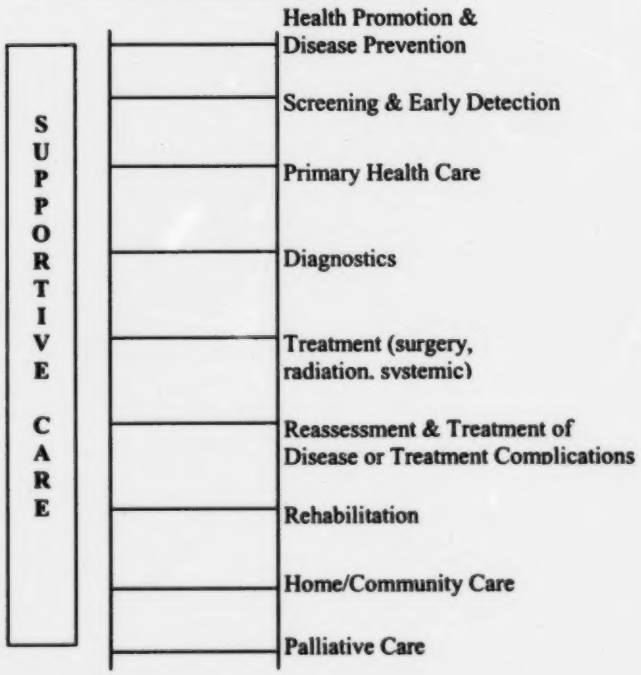
The structures that support the growing demand for cancer services over the next decade must champion a comprehensive integrated approach to care with clear authorities and accountabilities. These structures must help ensure timely access to quality care, and of utmost importance, be appropriate to meet the future needs that Ontarians will have for cancer services. It is recognized that these structures cannot be established in a vacuum. They must take into account the fact that Ontarians will make increasing demands on *all* health care services. As well, these cancer-related structures should not duplicate the work and efforts of other structures in the broader health services system, but rather support the appropriate and effective use of resources allocated for cancer care.

2. THE CURRENT SYSTEM OF CANCER SERVICES IN ONTARIO

BACKGROUND

A wide range of cancer services is provided by many organisations and individuals in Ontario (Figure 4). This chapter describes the types of cancer services that are provided, outlines the key providers of these services, and provides an overview of treatment activities in Ontario.

Figure 4: Continuum of Cancer Services



TYPES OF CANCER SERVICES

Health Promotion and Disease Prevention

Health promotion and disease prevention initiatives focus on reducing the incidence of cancer. Typically, these initiatives target environmental factors and lifestyle behaviours that have been linked to cancer such as pollution, hazardous substances, diet, tobacco and alcohol use, and exposure to sunlight. Health promotion and disease prevention initiatives include healthy public policy such as legislation on smoking and hazardous substances in the workplace/environment, and public campaigns that focus on changing individual behaviours.

Screening and Early Detection

Screening involves regularly examining high-risk individuals within a certain population group for the signs or symptoms of a disease (e.g., cervical cancer services). Some screening programs result in early detection of cancer, leading to more timely treatment and better outcomes.

Primary Health Care

Primary health care is the first level of care, and usually the first point of contact that people have with the health care system. Primary care includes disease prevention and health promotion, health assessment and diagnosis, treatment, coordination of and referral to other health care services, monitoring patients with cancer and palliative care.

Diagnostics

Diagnostics refers to the initial diagnosis and staging of cancer, and usually requires an evaluation of a tissue or body fluid specimen by a pathologist. Although the cancer diagnosis may be initiated by a primary care physician (e.g., a family physician orders a blood smear in diagnosing acute leukemia), it often requires referral to a specialist – a surgeon or radiologist – for a biopsy. After the initial diagnosis of cancer is confirmed by a pathologist who evaluates the tissue or body fluid specimen, it is usually necessary to undertake staging of the cancer to determine the extent of the disease at the time of diagnosis. The process of staging is complex and specific staging parameters are determined by the type of cancer. Staging may require evaluation of further pathology specimens from remote sites (e.g., bone marrow evaluation for leukemia or lymphoma) or radiographic imaging of remote sites as well as the site of initial disease presentation. Radiographic staging generally requires complex testing such as computerised tomography (CT), magnetic resonance imaging (MRI), or radionucleotide scanning (bone or liver scan). Diagnosis and staging are often completed prior to formulating a treatment plan. In some cases, critical information about staging is only available after surgical evaluation and resection of the tumour.

Treatment

Cancer treatment has three main modalities:

Surgery

Surgery is used both as an exploratory and diagnostic procedure and as a definitive treatment to remove cancerous growth. About 80% of cancer patient undergo an interventional or surgical procedure for diagnosis or treatment of cancer. Relatively few surgeons have practices that consist mainly or solely of cancer surgery. Rather, they tend to operate on a variety of conditions within their specialty.

Radiation

Radiation therapy is used to establish local-regional control of the growth of a tumour or to treat symptoms. Currently, about 35% of cancer patients get radiation at some stage of their disease. (International research indicates that 45-50% of cancer patients would benefit from this treatment.) Radiation is provided in designated radiation treatment facilities. It is a complex treatment modality requiring the involvement of a number of professional groups such as radiation oncologists, radiation therapists, physicists, physics technicians, nurses and support staff. Although there are high initial capital and ongoing operating costs, the evidence supports this treatment modality as being cost effective.[11] Radiation specialists confine their care to cancer patients.

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[11] "Radiotherapy in Sweden. A study of present use in relation to the literature and an estimate of future trends", *Acta Oncologica* Vol. 35 (8), 1996. Pp. 965-979.

Systemic Therapy (Chemotherapy)

Systemic therapy is the use of drugs that are effective against cancer to varying degrees. About 50% of cancer patients undergo systemic therapy with either anti-neoplastic or hormonal agents. Drugs are scientifically tested, approved and dispensed for clinical use within certain guidelines. Depending on the condition and the drug, systemic therapy can be provided in the hospital, out-patient or home setting. Systemic therapists may be specialists who confine their practices to cancer therapy or other physicians who have a wider practice that includes some systemic therapy patients. The latter are usually in regular contact with a cancer centre.

Reassessment and Treatment of Disease or Complications of Treatment

A characteristic feature of cancer management is that patients need to be reassessed periodically to detect the possible recurrence of disease or complications of treatment. This reassessment process is similar to the initial assessment of disease. Reassessment and treatment also includes monitoring of asymptomatic individuals.

Rehabilitation

Rehabilitation is an important enabler that helps cancer patients maximise their quality of life physically, cognitively, emotionally and socially. Rehabilitation, which can be provided in the hospital or in the community, helps cancer survivors achieve optimal functioning and quality of life. For example, there is good evidence to suggest that physical activity during systemic therapy leads to better outcomes. Currently, however, the health care system is ill-equipped to meet the rehabilitation needs of cancer survivors.

Home/Community Care

Home/community care is provided to people who are undergoing or have completed treatment for cancer. This care can include in-home management of pain and other symptoms as well as information, counselling and peer support for the patient and family (e.g., survivor groups). Typically, this care is co-ordinated through community care access centres (CCACs) with access to specific services varying by CCAC.

Palliative Care

Palliative care is provided to patients with advanced disease, and is focused on pain and other psychological and emotional support. This stage is managed by family physicians, cancer and palliative care specialists, nurses and social workers. Currently, the health care system is ill-equipped to meet the needs of people who require palliative care.

Supportive Care

Supportive care is the provision of the necessary services, as defined by those living with or affected by cancer, to meet their physical, informational, emotional, social,

psychological, spiritual and practical needs, during the pre-diagnostic, diagnostic, treatment and follow-up phases. Supportive care encompasses issues of survivorship, palliation and bereavement.[12] Currently, the health care system is ill-equipped to meet the needs of people who require supportive care.

KEY PROVIDERS OF CANCER SERVICES

The key providers of cancer services in Ontario are described below. [13]

Teaching and Community Hospitals

Teaching and community hospitals in Ontario provide a large proportion of cancer care in the province. These facilities enable cancer patients to receive care closer to home. Excluding host hospitals and the Princess Margaret Hospital (and the other two hospitals of the University Health Network – The Toronto General and Western hospitals) which are addressed below, teaching and community hospitals provide 72% of in-patient and same day cancer surgery in Ontario.[14] In addition, these facilities may have affiliation agreements with the regional cancer centres for the delivery of systemic treatment closer to home for patients who are initially seen in consultation with the regional cancer centre. It is unclear what proportion of hospital budgets are allocated for cancer-related care.

Cancer Care Ontario

Cancer Care Ontario (CCO) was created in April 1997. It is an operational service agency of the Ministry of Health and Long-Term Care, is governed by the *Cancer Act,* and operates within the context of a Memorandum of Understanding with the Ministry (November 8, 1999). CCO has its roots in the Ontario Cancer Treatment and Research Foundation (OCTRF) which was established by the *Ontario Cancer Treatment and Research Foundation Act* of 1943. OCTRF was mandated to take responsibility for the treatment, research and diagnosis of cancer. The Foundation controlled the delivery of radiation therapy in designated cancer centres. As medical oncology evolved, OCTRF assumed an active role in the provision of systemic therapy as well as radiation provided by designated centres. In 1995, the government announced that the mandate of OCTRF was to change. A new mandate and name change to Cancer Care Ontario was finalised in May 1997.

The new mandate expanded the organisation's role to include the full spectrum of cancer control by adding prevention and supportive care. The vision of CCO is to lessen the burden of cancer in Ontario by ensuring that all residents have timely, equitable access to an integrated system of excellent co-ordinated and efficient programs in prevention, early detection, treatment, education and research.

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[12] Definition provided by Cancer Care Ontario, December 2001.
[13] See Appendix E for additional detail on a number of these key providers.
[14] The Institute for Clinical Evaluative Sciences. Data for calendar years 1997-1999.

CCO has a provincial office in Toronto that supports eight regional cancer centres. Another centre is scheduled to open in 2002, with four more in various stages of planning.[15] The regional centres provide radiation and systemic therapy services. CCO centrally co-ordinates, funds, and employs the staff of these centres. Each regional centre has a CEO – a physician – who manages the resources locally.

Through the eight regional centres, CCO provides 75% of all radiation treatments in the province and 50% of all systemic treatments.[16] CCO operates the Ontario Breast Screening Program, the Ontario Cervical Screening Program, the New Drug Funding Program and the Ontario Cancer Registry. CCO also operates eight regional councils located across the province and a number of provider networks (see Appendix E).

In 2000/01, CCO had revenues of $284.4 million of which $244 came from the Ministry. CCO employs approximately 2,300 staff, most of whom work in the regional centres. CCO's budget for radiation services is $60 million per year, $30 million per year for systemic therapy services and $37 million for the provincial new cancer drug program.[17]

Host Hospitals

Each of the regional cancer centres is linked with a host hospital. These hospitals are either Academic Health Science Centres or major regional tertiary facilities. Host hospitals have expertise in and provide major services in cancer surgery, pathology, diagnostic services, in-patient care and cancer research. Some or all of these activities may be provided in partnership with the regional centres. The eight host hospitals provide 22% of in-patient and same day cancer surgery in Ontario.[18]

A few host hospitals and regional centres have joint venture agreements that reflect a comprehensive array of in- and out-patient cancer treatments. The majority of host hospitals and regional centres, however, operate relatively independently of each other. The extent to which there is functional, clinical and physician integration between the two organisations varies widely.[19]

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[15] The current regional cancer centres are Toronto-Sunnybrook Regional Cancer Centre (RCC), Hamilton RCC, London RCC, Windsor RCC, Northeastern Ontario RCC (Sudbury), Northwestern Ontario RCC (Thunder Bay), Kingston RCC, Ottawa RCC. A centre will open in Kitchener (Grand River) in 2002. Those being planned for the future include centres in the Peel, Durham, Niagara and Algoma areas.

[16] Cancer Care Ontario, *Operating Plan 2001/02*.

[17] Other funding sources include private donations, investment income, research grants, other grants, and other income. Other expenditures include cancer prevention, research and education, cancer system planning, and supportive infrastructure/administration.

[18] The Institute for Clinical Evaluative Sciences. Data for calendar years 1997-1999.

[19] Shortell at al. (1993, 1996) identified three types of integration. 1. Functional integration is the bringing together of support functions to benefit the health system (e.g., human resources, finance, purchasing, information systems). 2. Clinical integration is the degree to which health services are linked to ensure appropriate coordination, disease management, communication and the effective transfer of information and records. 3. Physician integration exists where physicians are economically linked to the health system and participate in the planning, management and governance of services.

Princess Margaret Hospital (University Health Network)

The Princess Margaret Hospital (PMH) is one of three hospitals that make up the University Health Network in Toronto. PMH has its roots in the *Ontario Cancer Institute Act, 1952* which established the Ontario Cancer Institute (OCI) with the mandate to plan, construct and establish buildings and other accommodations for research, diagnosis and treatment of cancer. In 1957, the *Ontario Cancer Treatment and Research Foundation Act* and the *Ontario Cancer Institute Act* were combined in a single statute called the *Cancer Act.* The object of OCI was revised to consist of the maintenance, management and operation of a provincial hospital with facilities for cancer research, diagnosis and treatment, being the Princess Margaret Hospital. In 1997, OCI amalgamated with the Toronto Hospital (*Toronto Hospital Act, 1997*), and Part II of the *Cancer Act* dealing with OCI was repealed. The Toronto Hospital subsequently changed its name to the University Health Network in 1999.

PMH and its research institute, the Ontario Cancer Institute, operate the largest cancer program in Canada. PMH provides medical oncology, high acuity systemic therapy, radiation and surgical oncology. PMH provides 25% of all radiation therapy in Ontario. It is the only facility to provide this service outside of CCO. PMH along with the Toronto Hospital and the Toronto Western (all part of UHN) provide 6% of in-patient and same day cancer surgery in Ontario (ICES, Calendar years 1997-1999). Even though PMH receives referrals from outside of Toronto, it does not have a formally designated regional or provincial role to provide cancer services.

Community-Based Providers

Community Cancer Clinics

There are 55 community cancer clinics located throughout the province. These clinics are connected with CCO through affiliation agreements with the regional centres. All of these offer follow-up for well patients who have received radiotherapy and/or systemic therapy. Some provide consultations by medical and/or radiation oncologists, and 44 clinics offer systemic therapy.

Family Physicians

Family physicians are important providers of cancer-related primary care and are an integral part of the continuum of care. They operate outside the scope of CCO. The role of family physicians includes prevention, screening and early detection, assessment and diagnosis, shared care during treatment and follow-up, psycho-social support, symptom control and pain management, and palliative care. In some rural and remote communities, systemic therapy is provided by family physicians under the supervision of a regional cancer centre.[20] It is unclear how much of family physicians' services are cancer-related.

[20] The Ontario College of Family Physicians, *The Role of Family Physicians in Cancer Care.* Provided by Jan Kasperski, Executive Director, November 19, 2001.

Community Care Access Centres (CCACs)

There are 43 CCACs in the province, all of which operate outside the scope of CCO. The services provided vary by CCACs. Some provide a community supportive role for cancer patients in their home which includes pain and symptom management, and palliative care. It is unclear how much CCAC activity is cancer-related.

Volunteer Organisations

The Ontario cancer services system depends greatly on the talents and generosity of volunteers. They supplement the efforts of care teams and are involved in comforting and supporting anxious patients. CCO has been very successful in attracting and supporting volunteers throughout the province. In addition, there are a number of volunteer organisations that support cancer services. Two examples are The Ontario Division of the Canadian Cancer Society and Wellspring.

The Ontario Division of the Canadian Cancer Society

The Canadian Cancer Society has over 100,000 members and is engaged in:

- Fund raising (a high proportion of money raised is given to the National Cancer Institute to fund cancer research);
- Public education especially in cancer prevention;
- Patient information including the Cancer Information Service in partnership with CCO (this service is partially funded by the Ontario Ministry of Health and Long-Term Care). This 1-800 service provides the public with up to date information on all aspects of cancer including the most current treatment options; and
- A province-wide volunteer driver program.

Wellspring

Wellspring is a voluntary organisation that is expanding rapidly. It provides supportive care to cancer patients and has grown from one centre in Toronto to five centres across Ontario over two years.[21]

OVERVIEW OF TREATMENT ACTIVITY

SURGERY

Table 1 indicates that the majority of in-patient and same day cancer surgery – 72.4% – is conducted at hospitals other than the host hospital and PMH/UHN.

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[21] The sites are in central Toronto, at Sunnybrook and Women's College Health Sciences Centre, Oakville, London and Niagara/Thorold.

Table 1: In-patient and Same Day Oncology Surgery for Adults (18+) 1997-1999 (Calendar Years)*

Other Hospitals		Host Hospitals		Princess Margaret Hospital/University Health Network	
69,778	(72.4%)	21,095	(21.9%)	5,540	(5.8%)

*Source: Institute for Clinical Evaluative Sciences. Multiple surgical procedures within one admission are counted as a single event.

Table 2 illustrates that the volume and intensity of cancer care are not distributed equally across hospitals. For example, in the Greater Toronto Area (GTA) and Hamilton, PMH/UHN conducts 27.2% of surgery (as measured by weighted cases).[22] Only five hospitals account for 51.4% of all surgical weighted cases. In terms of case complexity, PMH/UHN conducts almost 2/3rd of quaternary and 1/3rd of tertiary cancer surgery.

Table 2: Surgical Oncology in the Greater Toronto Area and Hamilton (CMG99) – Percentage of Weighted Cases (Hospitals With the Top Five Volumes in Each Category)*

Hospitals	Oncology All	Quaternary	Tertiary	Secondary	Primary
PMH/UHN	27.2%	63.2%	34.9%	17.6%	8.6%
Sunnybrook	8.1	6.2	8.7	8.2	~
Sick Children's	6.5	20.1	8.7	~	~
St. Michael's	4.9	1.4	5.6	~	~
Humber River	4.7	~	~	5.6	6.9
Hamilton HSC	~	5.7	~	~	~
Scarborough Gen	~	~	4.8	~	~
North York General	~	~	~	6.0	10.0
Lakeridge	~	~	~	5.2	~
Toronto East Gen	~	~	~	~	7.0
Trillium	~	~	~	~	7.2
Total	51.4%	96.6%	62.7%	42.6%	39.7%

*Oncology "flag" developed by Bob Bell, Sarah Downey and staff in Utilisation Management at UHN. Underlying data source is CIHI 1999/00.
~This table only presents the hospitals with the top five volumes in each category. Blank cells indicate that these hospitals were not one of the top five volume hospitals, and may have had some or no surgical oncology activity.

Table 3A, B, C: Ontario Surgical Oncology Weighted Cases OCOTH and Non-OCOTH Hospitals, 1999/2000

Tables 3A, B and C show the proportion of oncology and non-oncology weighted cases in Ontario's teaching hospitals (OCOTH – Ontario Council of Teaching Hospitals).

[22] The measure *weighted case* reflects the fact that not every patient or case requires the same type or quantity of health care resources. The higher the weighted case, the more resources required.

Table 3A indicates that about 15% of weighted cases at teaching hospitals are for oncology compared to 8.6% in non-teaching hospitals. These proportions are relatively similar for day surgery as indicated in Table 3B (9.8% for teaching and 8.6% for non-teaching). The combined activity for acute care and day surgery indicates a higher percentage of oncology weighted cases in teaching facilities – 14.2% to 8.6% in non-teaching facilities (Table 3C).

Table 3A: Surgical Oncology – Acute Care*

	Oncology Weighted Cases	Non-Oncology Weighted Cases	Percent Oncology
OCOTH	80,772.76	546,530.64	14.8%
Non-OCOTH	86,696.6	1,005,418.21	8.6%
	167,469.36	1,551,948.86	10.8%

Table 3B: Surgical Oncology – Day Surgery*

	Oncology Weighted Cases	Non-Oncology Weighted Cases	Percent Oncology
OCOTH	6,493.57	65,969.32	9.8%
Non-OCOTH	13,510.42	157,205.52	8.6%
	20,003.99	223,174.84	9.0%

Table 3C: Surgical Oncology – Combined Acute Care and Day Surgery*+

	Oncology Weighted Cases	Non-Oncology Weighted Cases	Percent Oncology
OCOTH	87,266.33	612,499.96	14.2%
Non-OCOTH	100,207.01	1,162,623.73	8.6%
All	187,473.35	1,775,123.69	10.6%

*Source: Bob Bell, Princess Margaret Hospital. 1999/2000 CIHI DAD using all qualifying and non-qualifying cases with Oncology as a Primary ICD9 diagnosis. RIW99 used to calculate weighted cases. OCOTH hospitals include: Hamilton Health Sciences Centre, Hospital for Sick Children, Kingston General Hospital, London Health Sciences Centre, Mount Sinai Hospital, The Ottawa Hospital, St. Joseph's Hospital (Hamilton), St. Joseph's Hospital (London), St. Michael's Hospital, Sunnybrook and Women's College Health Sciences Centre, University Health Network.
+University Health Network accounts for 10% of surgery weighted cases in Ontario.

RADIATION

The following table provides radiation volumes for Cancer Care Ontario and Princess Margaret Hospital. Different terms are used by both organisations. PMH's term, "courses" is probably closest to CCO's term, "new case visits", but is not exactly comparable.

Table 4: Radiation Volumes

Measure	2000/01 Actual	Annual Growth since 1997/98
Princess Margaret Hospital*		
Radiation Therapy Courses	7,900	12%
Cancer Care Ontario+		
New Case Visits	21,491	8%
Treated Cases	19,077	7%

*Source: Bob Bell (Princess Margaret Hospital)
+Source: Cancer Care Ontario, *Operating Plan 2001/02.*

SYSTEMIC THERAPY

Tables 5, 6 and 7 provide systemic therapy volumes for CCO and PMH/UHN. Different terms are used by both organisations. PMH's term, "daycare visit" is the same as CCO's term, "suite visit".

Table 5: Systemic Volumes (Cancer Care Ontario)*

Systemic	1999/00 Actual	2000/01 Actual	% Change
New Case Visits in Regional Cancer Centres and Host Hospitals	14,023	14,311	2%
Suite Visits in Regional Cancer Centres and Host Hospitals	94,061	99,283	6%
Community Systemic Therapy New Case Visits	1,060	1,123	6%

*Source: Cancer Care Ontario, *Operating Plan 2001/02.*

Table 6: Systemic Treatment Activity: Projected Annual Growth (Cancer Care Ontario)*

Systemic	Annual growth+
Total Antineoplastic Cases	6.0%
Total Suite Visits	12.0%
Total Number of Clinic Visits	9.0%

*Source: Ian Brunskill, Cancer Care Ontario.
+Annual growth per annum over 1997/98 to 2000/01.

Table 7: Systemic Therapy Day Care Volumes (Princess Margaret Hospital/University Health Network)*

	Volume	% Increase
1999/2000	18,750	
2000/2001	20,400	8.8%

*Source: Bob Bell, Princess Margaret Hospital.

THE COMMITTEE'S OBSERVATIONS

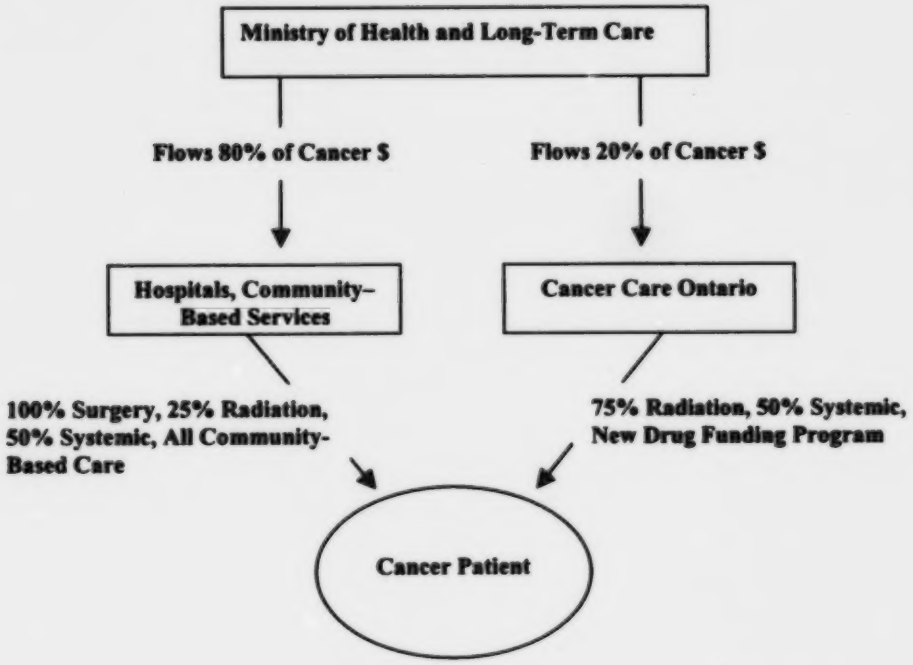
A wide range of cancer services is provided in Ontario. The volume of services provided and the location varies by the service. For example, radiation activity is provided by two key players – Cancer Care Ontario and Princess Margaret Hospital. As a result, it is easier to determine the volume of radiation provided throughout the province and ascertain where there are gaps in service. Determining systemic therapy activity levels is more difficult, with surgery levels being the most difficult to determine. Although many hospitals conduct exploratory and definitive cancer surgery, and provide systemic therapy, activities are not consistently measured nor routinely tracked by a centralised agency.

The largest gaps in knowledge about cancer service activity are typically those areas of the continuum that are not treatment-related. It is unclear the extent to which there are cancer-related activities at the local and regional levels in health promotion and disease prevention, screening and early detection,[23] primary care, home/community care and palliative care. More importantly, it is unclear the extent to which there are *gaps* in these services throughout the province and where patient-focused care is being compromised.

The complex array of cancer services is provided by many players. The perception is that this array of providers may not be pulling together as an integrated cancer care team. What it also suggests is the lack of a provincial organisation that has a comprehensive overview of all parts of the cancer system as well as the whole (Figure 5).

[23] The Ontario Breast and Cervical Screening Programs are offered at various sites.

Figure 5: Cancer Funding and Activity in Ontario


Ministry of Health and Long-Term Care
Flows 80% of Cancer $
Flows 20% of Cancer $
Hospitals, Community–Based Services
Cancer Care Ontario
100% Surgery, 25% Radiation, 50% Systemic, All Community-Based Care
75% Radiation, 50% Systemic, New Drug Funding Program
Cancer Patient

PART TWO: THE ISSUES

3. INTRODUCTION TO THE ISSUES

Part Two of this report presents the major issues that the Committee discussed and debated. These issue chapters are:

- Governance, management and advisory structures to support integration of and accountability for cancer services.
- Best practices and quality outcomes for cancer services including quality mechanisms that are needed at the provincial, regional and local levels.
- Funding arrangements that support cancer care delivery as well as physician services, and the accountability for these funds.
- Information systems needed to support the management of cancer services, and the maintenance of standards and best practices in cancer care.
- Human resource arrangements and proposed strategies to ensure a sufficient number of providers in the future.
- Patient- and provider-focused education and communications to support continuous communications.
- Research activity and initiatives to promote continued research endeavours.
- New technologies and pharmaceuticals in cancer services.

For each issue, background information is presented to familiarise the reader with the facts behind the issue. This descriptive section is followed by the Committee's observations and recommendations.

4. GOVERNANCE, MANAGEMENT AND ADVISORY STRUCTURES TO SUPPORT INTEGRATION AND ACCOUNTABILITY

BACKGROUND

Governance, Management and Advisory Roles

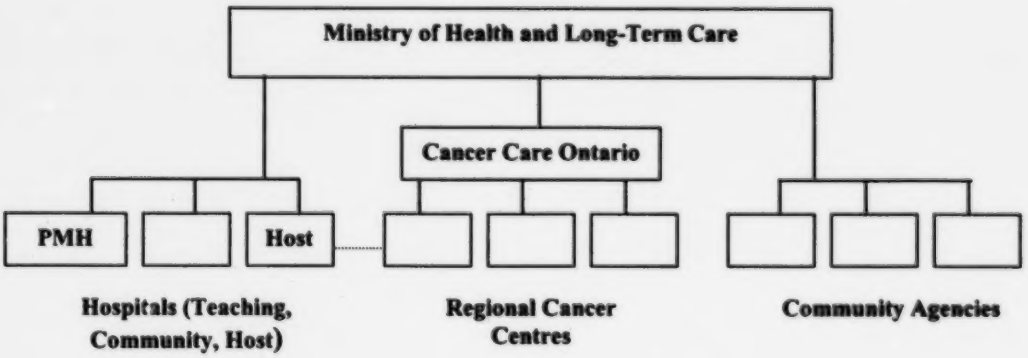
Governors, managers and advisors play different roles and have different accountabilities.

Governance refers to leadership, and the act of setting strategic directions, priorities and supporting policies. A Board of Governors is accountable for quality and performance, and has budgetary control over operations. Management is accountable to the Board for the performance of the organisation and for operationalising the Board's decisions. Advisors and advisory bodies neither govern nor manage rather they provide information, opinions and recommendations on issues based on evidence and experience.

Governance, Management and Advisory Accountabilities for Cancer Services

Governance, management and advisory accountabilities for cancer services in Ontario are complex. Key players with these accountabilities include other teaching and community hospitals, Cancer Care Ontario, host hospitals and Princess Margaret Hospital (Figure 6).

Figure 6: Current Organisation of Cancer Services in Ontario



Teaching and Community Hospitals (Excluding Host Hospitals and PMH/UHN)

Teaching and community hospitals in Ontario conduct cancer surgery and may have agreements with the regional cancer centres for the delivery of systemic therapy. The cancer services provided by these teaching and community hospitals are governed and managed by the hospitals. These hospitals operate under the *Public Hospitals Act*, submit annual operating plans to the Ministry, and are accountable to their boards (and ultimately the Minister) for the quality of services they provide (Figure 7).

Figure 7: Governance, Management and Accountability in Hospitals

Cancer Care Ontario

CCO has advisory, governance and management accountabilities specifically for cancer services. CCO is the province-wide cancer agency mandated by the government of Ontario to be the principal advisor to the Minister on all matters relating to the cancer control system and its services (see Appendix F for CCO's objectives and mandate). CCO is also mandated to provide certain cancer control services through regional cancer centres as well as some provincial cancer programs (e.g., prevention and screening

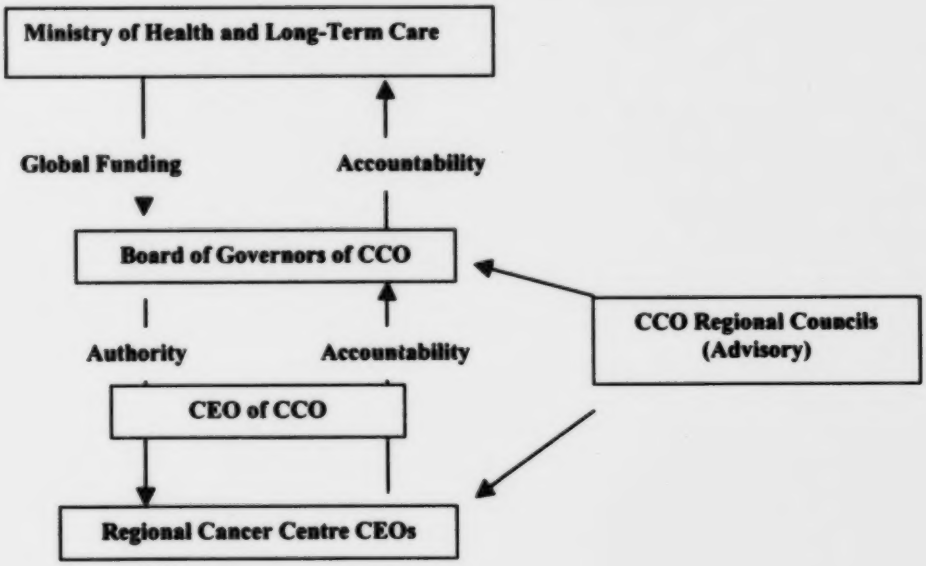
programs). CCO manages the staff and operations of eight regional cancer centres. CCO has a board with 25 members appointed by Order in Council.

Each of the regional centres has a Cancer Care Ontario Regional Council (CCOR) established under CCO by-law, which is responsible for the coordination of cancer control services, the promotion of standards and guidelines on a regional basis, and the promotion of appropriate patient access to cancer facilities.[24] CCORs carry out these functions through affiliation agreements between regional centres, and host hospitals and smaller community hospitals. The chair of each CCOR sits on CCO's board.

Regional centres provide infrastructure support for the CCOR. Managers of regional centres are accountable to CCO's central office. Both CCORs and regional centres are ultimately accountable to the CCO board.

CCO is classified as an Operational Service agency of the government of Ontario. CCO operates under *The Cancer Act* and a Memorandum of Understanding with the Ministry. It also submits annual and multi-year operating and business plans to the Ministry. As a proportion of the provincial budget spent on cancer services, CCO governs and manages less than 20% of all services related to cancer assessment, treatment and follow-up (Figure 8).[25]

Figure 8: Governance, Management and Accountability in CCO



[24] *Memorandum of Understanding* made the eighth day of November, 1999 between the Ministry of Health and Long-Term Care (Ontario) and Cancer Care Ontario.

[25] This is CCO's budget of $284.4 million out of an estimated $1.5 billion spent on cancer services in Ontario.

Host Hospitals

Each of the regional cancer centres is linked with a host hospital through an agreement that varies with each centre. The cancer services provided by host hospitals are governed by the hospitals' boards and are managed by the hospitals' senior management teams. In some instances, the CEO of the regional centre is a vice-president of the host hospital and manages all its cancer services. Host hospitals operate under the *Public Hospitals Act*, submit annual operating plans to the Ministry, and are accountable to their boards (and ultimately the Minister) for the cancer services they provide (see Figure 7).

Princess Margaret Hospital (University Health Network)

Princess Margaret Hospital is the largest cancer centre in Ontario and indeed in Canada. It provides radiation, systemic therapy and surgery treatments. PMH's cancer services are governed by the board of UHN and a PMH board subcommittee. The hospital's cancer services are managed by a Chief Operating Officer. PMH operates under *The Toronto Hospital Act, 1997* and the *Public Hospitals Act*, submits an annual operating plan to the Ministry, and is like other public hospitals, accountable to the board of UHN (and ultimately the Minister) for the cancer services it provides.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

Challenges for Integration and Accountability

The cancer services system is characterised by many governors and managers who oversee pieces of the system. Although there is a wide range of accountability mechanisms to guide these activities, this situation presents challenges for integrating services, providing patients with seamless care, and identifying and meeting key accountabilities at the provincial, regional and local levels.

Provincial Level

At the provincial level, there is no one agency that governs the provincial cancer system. CCO does not have the authority to *govern* the system. This has had two major consequences. One, CCO has not played a leadership role in setting strategic directions, priorities and policies for the entire provincial cancer services system. Similarly, it has not developed system-wide standards, evaluated the system, or focused on integrating and co-ordinating cancer services across the province. Two, there is confusion at the provincial level about who is accountable for key activities and outcomes that impact on patient care. These include ensuring timely and equitable access to care, accountability for resources to support the full continuum of cancer services, and accountability for the complete course of prevention, screening, primary care, diagnosis, treatment (surgery, radiation, systemic therapy), rehabilitation, home/community care, supportive and palliative care.

This situation is also reflected in management. There is no provincial management nor is there a common organisational structure to manage cancer services. Although this allows flexibility to meet local circumstances, there is no one agency that monitors the appropriateness and audits the effectiveness of management arrangements to ensure that patient needs are met.

Regional Level

There is no agency that is responsible for integrating cancer services at the regional level. Although the regional cancer centres use the term "regional," they do not have the authority to govern or manage the system at this level. The Committee observed that there is a lack of common understanding among the regional centres about their roles and responsibilities. Although there are various joint venture and affiliation agreements between regional centres and host hospitals, and between regional centres and local facilities, these agreements play a limited role in furthering system integration and widespread co-ordination across the continuum of care. The Committee also noted that in instances where the services of regional centres and host hospitals are not well integrated, there may be administrative inefficiencies. Greater efforts are needed to clarify accountabilities and maintain smooth administrative practices. More importantly, greater efforts are needed to co-ordinate care for the cancer patient since he or she will likely have two medical records and care provided by staff of two different employers.

At the regional level, CCORs do not have regional governance nor management authority. The Committee's observation that there is a lack of common understanding about the advisory and facilitative role of CCORs, was confirmed in a recent review which found that an ambiguous mandate, authorities and accountabilities were key issues for CCORs.[26] The role of CCORs in relation to district health councils (DHCs) also adds to role confusion. Although CCORs are expected to play a role in planning regional cancer services, DHCs have a legislated responsibility for regional planning of services. A further complexity is the existence of community care access centres and Ministry regional teams that typically do not participate with CCORs in the regional coordination of cancer services.

Local Level

At the local level, hospitals have boards of directors who govern and oversee the management of their cancer services. Although there is accountability to the Ministry through hospital operating plans, these plans may not highlight the current level of cancer services and proposed changes in service. Furthermore, how local service decisions are made within a regional and provincial context is unclear. For example, hospitals are not required to inform CCO of proposed cuts in cancer services which may result from financial pressures on hospitals.

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[26] Maureen Quigley and Associates Inc., *A Review of Cancer Care Ontario Regional (CCOR) Councils.* Prepared for Cancer Care Ontario, October 31, 2001.

Regional centres report to CCO rather than operate under a local community governance system. Managers of regional cancer centres are accountable to CCO's central office and the CCO board.

Responsibility for the full continuum of care is assumed to rest at the regional and local levels. For example, physicians are accountable for the individual episodes of care of their patients, whether it be primary care in the local community or specialised services in the region. As well, the provision of primary care, prevention, home care and palliative care for cancer patients is typically determined at the local level. The degree to which this responsibility is being met throughout the regions in Ontario is unclear since there are no formal accountability mechanisms to monitor the situation.

A Governance and Management Structure to Support Integration and Accountability

The Committee examined various models of cancer service in other provinces (Alberta, British Columbia and Quebec) and internationally (Australia, New Zealand and the United Kingdom). It also examined a model proposed by CCO, and the integrated models of the Ontario Co-ordinated Stroke Strategy and the Cardiac Care Network of Ontario. This latter model was of particular interest because of CCN's structure and accomplishments.

CCN is a partnership of health professionals, hospitals and government that focuses on appropriate and timely access to adult cardiac services by patients and their physicians. CCN advises the Ministry and co-ordinates the provision of some advanced cardiac services for adult Ontarians. CCN's efforts were initially limited to tertiary care cardiac surgery but it has been expanding its focus. It has collected data on cardiac surgery for a number of years and has recently begun to collect data on cardiac catheterization, angioplasty and stent procedures. CCN is in the process of expanding its database to include pacemakers, implantable cardiac defibrillators and cardiac rehabilitation.

The Committee was very impressed at the efficacy of this organisation, noting that cardiac waiting lists and other politically sensitive issues have not received media attention for many years, and that difficult supply/demand issues are well handled by this organisation. Although CCN has not yet achieved full integration of cardiac services, the Committee observed that key components of the CCN model and its approach were relevant to strengthening the cancer services system:

- CCN is essentially run by the providers of service from around the province. There is no governing board at the provincial and regional levels. As well, CCN has no financial or governance authority over the cardiac centres in Ontario.
- CCN exerts its influence by peer pressure and by advising the Ministry on funding of Ontario cardiac centres. This is a critical incentive to achieve both quality and quantity of care at the regional and local levels.

- The central decisions are made by the providers, ensuring buy-in and application to data gathering and analysis. Best practice and quality standards are prescribed by CCN.
- CCN members have concentrated on developing a valid and reliable database with clear definitions (e.g., urgency rating score), as well as a broad range of guidelines using a collaborative, consensus-driven approach.
- CCN's operation is data-driven and transparent through public reporting of hospital-specific and system performance.
- Even though CCN lacks a governance board and has no direct financial control over cardiac centres, it is a component of a cardiac system which, by risk-adjusted measurements, yields results amongst the best in the world.

The Committee spent a great deal of time discussing the most appropriate governance and management structure that would support integration of care for patients and clear accountabilities. It was agreed that the recommended structure must build upon the positive aspects of the current system as well as address its limitations. It was also agreed that the structure must identify clear accountabilities at the provincial, regional and local levels.

The Committee discussed four basic governance, management and advisory options:

1. Establish a system of Regional Health Authorities.
2. Expand the role of CCO for all cancer services.
3. Expand the role of hospitals for all cancer services.
4. Strengthen CCO's role as advisor and standard setter for all cancer services, and strengthen the role of regional entities for quality and coordination.

It must be noted that the Committee debated at length a number of variations of these options. The key features of the four *basic* options and a summary of the Committee's observations are presented in Table 8.

Table 8: Governance, Management and Advisory Options

	Key Features	Summary of Observations*
Option 1: Establish a system of Regional Health Authorities	Establish a system of regional health authorities and give each region a funding envelope to pay for all health services in the region. Governance and management of cancer care determined by the regional authority.	This option would ensure that cancer services address local needs. The challenge is that cancer would be set up as a separate "silo" since Ontario does not have regional health authorities. The lack of a recognised regional system makes the success of this option unlikely at the present time.
Option 2: Expand the role of CCO	Expand CCO's role by giving it governance and management authority for all in- and out-patient cancer care, and responsibility for linking with host and community hospitals, community-based	This option would establish one body with clear delegated authority for governing and managing the system in a consistent fashion. The challenge is that it would eliminate local governance authority and accountability to the community for cancer services, probably lead

	Key Features	Summary of Observations*
	providers, and community advisors in each region.	to a decrease in local community support, and result in cancer services that are not integrated with other hospital services. The fact that CCO would need to expand its authority over 80% of the cancer system that it does not currently govern/manage, makes the success of this option unlikely.
Option 3: Expand the role of hospitals	Expand the role of teaching and community hospitals to include governance and management authority for all in- and out-patient cancer care that they provide, and responsibility for linking with other community hospitals, community-based providers and community advisors in each region.	This option would establish local governance and management authority to the local community for all cancer services, and support the integration of in- and out-patient care. The challenge is that hospitals lack the regional mandate that is required to advance regional integration and coordination of cancer services among the wide range of providers in the region. It would also result in system destabilisation, since all regional centres would need to be integrated into hospital operations.
Option 4: Strengthen CCO's role as advisor and standard setter for all cancer services, and strengthen the role of regional entities for quality and coordination	Maintain the governance and management systems that currently exist for cancer services. Strengthen the provincial advisory and standards setting role of CCO and the role of regional entities for co-ordinating in- and out-patient cancer care provided by regional centres, hospitals and community-based providers.	This option recognises one organisation that would advise government on all cancer services and be responsible for setting and maintaining standards for all cancer services. The option also supports a strong regional voice in quality and service coordination. The challenge is that CCO must re-focus its efforts on strengthening regional networks and supporting their efforts to meet local needs.

* See Appendix G for pictorial depictions of these models.

The Committee supported option 4 as the most feasible governance, management and advisory structure to support integration and accountability in the cancer services system, *at this time*. This option maintains the current governance and management systems that exist for cancer services. CCO's role as advisor and standard setter for *all* cancer services is strengthened, as is the role of regional bodies for quality and coordination.

The selection of this option took into account the current realities of Ontario's health care system, and was sensitive to the need for the appropriate conditions and timing to support and sustain system change. Ontario does not have a formal regionalised system of health care which is necessary to support option 1. In addition, many hospitals are still grappling with the consequences of restructuring, and have ongoing pressures to meet health care budgets Options 2 and 3 would add to further destabilisation in the system by

shifting governance and management authority for cancer care either to CCO or to hospitals. These shifts would have impacts on local communities, the level of program and system integration that could be achieved, and human resources. Option 4 minimises system destabilisation, incorporates some key components of other models studied (such as the Cardiac Care Network) and meets the criteria that the Committee used to guide its deliberations. This option will ensure:

- Quality care that supports the important role of patients/clients and their families as participants in that care, that meets the needs of these individuals, and upholds best practices;
- Timely, equitable and appropriate access to comprehensive cancer services;
- A system of integrated and co-ordinated services that supports a seamless care experience for the patient throughout the course of the disease;
- Clear accountability for the planning, provision and auditing of quality care, timely access to appropriate services, effective outcomes and performance improvements;
- Effective and efficient provision of services that makes the best use of human, financial, information and technological resources; and
- Conditions that attract and retain sufficient appropriately qualified care providers.

The essential elements of the governance, management and advisory model that must be in place to ensure its successful implementation are:

- CCO as a provincial advisor and strong central agency with a clear provincial focus on the *whole* cancer services system;
- Strong regional activity to ensure that local services meet the needs of the community for integrated quality cancer care; and
- Tools to support the governance and management model.

CCO as a Provincial Advisor and Strong Central Agency with a Clear Provincial Focus on the Whole Cancer Services System

As the principal advisor on the cancer control system and its services, CCO has given cancer a profile in the political and public arenas. It has successfully advised government for the development of new regional centres to meet growing needs.

The Committee observed that CCO has had variable success in fulfilling its role as principal advisor to the Minister. Since CCO governs and manages only a certain proportion of cancer services, the perception is that the organisation may be overly focused on advocating for these services rather than for all cancer services. This situation is heightened by the Ministry's designation of cancer as a priority program. Typically, this designation is associated with protected funding. The only funding that the Ministry "protects" for the wide range of cancer services is CCO's operating budget. When CCO advocates for funding increases, it is primarily advocating for a limited proportion of the system rather than for all cancer services. In addition, since CCO's funding is only protected for cancer services, the designation of cancer as a priority program is not fully

realised in any other organisation that provides services to people at risk of and who have cancer.

The Committee believes that it is critical for CCO to strengthen its role as principal advisor to the Minister on *all* matters relating to the cancer control system and its services. CCO must have its finger on the pulse of the whole cancer system by providing comprehensive and strategic advice that is objective, based on an analysis of needs and evidence, and involves the active participation of its stakeholders in building consensus. It is recognised that CCO must have a number of tools at its disposal to fulfil this role successfully. For example, access to clinical and management information at the provincial, regional and local levels is necessary. (This is addressed in greater detail in the chapter, *Information*.) In addition, CCO must refocus its energies on key strategic provincial priorities that focus on access to quality care for the patient.

The Committee recommends that:

R1 **The role of Cancer Care Ontario be strengthened as principal advisor to the Minister of Health and Long-Term Care on all matters related to the cancer control system and cancer control services. CCO must provide comprehensive and strategic advice to the Minister that is objective, and based on an analysis of needs and evidence, and involves the active participation of its stakeholders in building consensus. This advice should focus on the cancer services system and address current and future issues at the provincial, regional and local levels.**

CCO will continue to allocate Ministry funds to the regional cancer centres. (The issue of management is addressed in more detail in the next section on strengthened regional activity.) Although CCO will continue to govern directly about 20% of cancer services in the province, it will be expected to play an influential advisory role to the Ministry on system planning and funding of all cancer services. To succeed, CCO's provincial advisory quality and performance role must be recognised by the Ministry and all providers of cancer services in the province.

Consistent with strengthening CCO's role as advisor on all cancer services, the Ministry needs to have a consistent policy on defining cancer as a priority program. The policy must go beyond the current limited activities of CCO and recognise the continuum of cancer services and the activities of the other key providers of these services. Enhancing the definition of cancer as a priority program should be clearly communicated to all facilities and professionals providing cancer services. The change will require tangible shifts in how cancer services are funded and provided by health care organisations that typically have a variety of responsibilities in addition to cancer. (This issue is addressed in greater detail in the chapter, *Funding*).

The Committee recommends that:

R2 The Ministry of Health and Long-Term Care designate the broad continuum of cancer services as a provincial priority program. This designation should be communicated to all facilities and professionals who provide cancer services in Ontario.

In addition to its advisory role, the Committee agreed that CCO must focus on and be accountable for providing strategic direction for the cancer services system, developing standards and guidelines to support quality cancer care across the continuum, monitoring system performance, and addressing problem areas. (This is explored further in the chapter, *Best Practices and Quality Outcomes*.) CCO must also be accountable for ensuring timely and equitable access to care provincially, and the effective use of resources to support the full continuum of cancer services including prevention, early detection, primary care, diagnosis, treatment (surgery, radiation, systemic therapy), rehabilitation, home/community care, supportive and palliative care. How well the system is performing should be transparent and publicly reported.

The Committee recommends that:

R3 Cancer Care Ontario focus on and be accountable for providing strategic direction for the cancer services system, developing standards and guidelines to support quality cancer care across the continuum, monitoring system performance, addressing problem areas, ensuring timely and equitable access to care, ensuring the effective use of resources to support the full continuum of cancer services, and publicly reporting on system performance.

CCO should continue to have a board that advises the Ministry on strategic directions, priorities and supporting policies for the cancer services system, is accountable for system quality and performance, and governs those services over which it has budgetary control. Since the Committee believes that CCO should focus its efforts on the broader system, the appropriateness of the Board's current structure and selection process should be reassessed. The Board needs to have broad strategic, executive and clinical expertise. Greater flexibility in selecting Board members with the required skills should be considered.

The Committee recommends that:

R4 The Ministry of Health and Long-Term Care, in partnership with Cancer Care Ontario, review the current structure and selection process of the CCO board to ensure that these are appropriate for obtaining the strategic, executive and clinical expertise required on the board to support CCO's role, as recommended in this report.

Strong Regional Activity to Ensure that Local Services Meet the Needs of the Community for Integrated Quality Cancer Care

The Committee agreed that there must be a strong regional focus and accountability for the provision of cancer services so that patients receive integrated and co-ordinated cancer care closer to home. The regional system should be strengthened in two ways:

- Establish regional cancer advisory bodies; and
- Enhance and integrate the activities of regional cancer centres

Establish Regional Cancer Advisory Bodies

The Committee believes that regional cancer advisory bodies should be established to advise on planning and integrating all regional cancer services. The ultimate goal of the regional bodies is to facilitate discussion and decision-making among organisations involved in cancer services so as to improve the quality and integration of these services in the region. The regional bodies should be sensitive to the needs of the local community and have flexibility to meet local needs.

The regional bodies should be responsible for:

- Monitoring compliance with provincial standards and guidelines for in- and out-patient care;
- Evaluating the performance of the cancer services system in the region (e.g., CCO will provide provincial data to the regional bodies to evaluate regional performance);
- Monitoring and advising on opportunities to improve clinical and system performance (e.g., wait list monitoring and management, monitoring medical outcomes);
- Understanding the money spent within the region on cancer care and advising CCO on regional cancer funding;
- Linking funding recommendations to outcome and performance measurement;
- Conducting population health planning to determine the need for cancer services in the region; and
- Reporting to the public and CCO on regional cancer care in such areas as waiting, access, integration of care, and the quality of the patient experience as he or she moves through the system.

The regional bodies will report to the CCO Board.

It is proposed that the regional bodies replace the current CCORs. It must be noted that the mandate and responsibilities of the proposed bodies are similar to that of CCORs described in detail in a 1997 report of the Ministry Transition Team.[27] Although CCORs have many accomplishments, generally they have not been completely successful in achieving their goals. The reasons include:

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[27] *Report of the Cancer Transition Team: Recommendations for Creating Cancer Care Ontario.* Submitted to the Deputy Minister of Health, January 6, 1997.

- Lack of sufficient staff and financial resources to support their work;
- Ambiguity in their mandate, authority and accountability;
- Lack of CCO awareness of and commitment to the activities, achievements, issues and concerns of the CCOR regions;
- Inability to share best practices across CCOR regions;
- Understanding of regional differences; and
- Lack of coordination in the funding of cancer services in the region.[28]

The Committee supports the establishment of regional bodies with the following in place:

- Information technology (centralised management information system that would be accessed by the regional bodies to evaluate system performance);
- Staff resources to help oversee and co-ordinate the activities of each regional network and support the work of the regional body;
- A greater focus on obtaining regional input to make regional recommendations about cancer services (this must be supported with authority to obtain information from all stakeholders in a timely manner);
- Greater responsibility for monitoring the implementation of standards and guidelines, and overseeing the quality of services and the performance of providers;
- Broad-based, balanced representation of providers in the region on the regional bodies including representatives of hospital- and community-based care, DHCs and CCACs (these appointments should be made for the expertise that a person brings rather than the role the person plays); and
- Active participation of consumer representatives and a senior regional official from the Ministry on each regional body.

A number of key elements are critical for the success of the regional bodies. One is a cultural and attitudinal shift away from a centralised CCO-based authority to regional accountability and sensitivity to local needs. This shift in focus will help address the perceived problem that CCO is neither aware of nor committed to the activities, achievements, issues and concerns of the regions. A second key element is recognition of the role of the regional cancer bodies by the Ministry, all providers of cancer services and the public. These players should be active participants on regional bodies. Indeed, the proposal to regionalise planning and to improve patient care should support volunteer efforts on a local and regional basis. The Committee recognises and lauds the volunteer efforts in this province, part of a huge and proud tradition in our society, and encourages recognition of this contribution to the fulfillment of this new plan.

The Committee recommends that:

R5 Regional Cancer Advisory Bodies be established by the board of Cancer Care Ontario to plan and oversee, on an ongoing basis, the integration of all regional cancer services. These bodies should be accountable to CCO for integrating and co-ordinating cancer services regionally, implementing standards and guidelines in the regions, overseeing the quality and

[28] Maureen Quigley and Associates Inc., *Ibid.*

performance of services, and providing advice to CCO on regional cancer funding. This information should be communicated to regional stakeholders. To help ensure the success of the Bodies they should: i) have adequate resources to support information technology and staff; ii) have a strong focus on obtaining regional input; iii) have responsibility for monitoring the implementation of standards and guidelines, and overseeing the quality of services and the performance of providers; iv) have broad-based, balanced representation of providers in the region; and v) include the active participation of consumer representatives and a senior regional official from the Ministry of Health and Long-Term Care.

Enhance and Integrate the Activities of Regional Cancer Centres

The Committee believes that it is important to *enhance* the activities of regional cancer centres in relation to CCO. The current perception is that CCO is too focused on directly managing the activities of the centres. Although legally CCO cannot delegate its governance authority to the regional centres, it can delegate more operational authority to the centres for local decision-making. CCO could maintain central governance authority without central management.

Enhancing the activities of the regional centres is critically important to support the development of a regionalised system of cancer services. The regional centres will be expected to support the regional cancer bodies and actively facilitate the other providers in the region to determine local solutions for the provision of cancer services. Regional centres will provide leadership by working collaboratively with and building consensus in the entire community, establishing alliances and joint ventures, and moving the region toward improved coordination of cancer services consistent with provincial frameworks.

The Committee recommends that:

R6 The activities of the regional cancer centres be enhanced in two ways: i) CCO should delegate more operational authority to the regional cancer centres for local decision making; and ii) the regional cancer centres should support the regional cancer bodies and actively facilitate the participation of other cancer service providers in the region.

Although the Committee has maintained the regional centres and host hospitals as separate entities, it believes that there must be a move to *integrate* the activities of regional cancer centres more closely with those of the host hospitals. Currently, agreements between regional centres and host hospitals vary widely, ranging from delivery of an integrated cancer program to delivery of quite distinct programs by two separate organisations. Efforts must be made to develop management processes that make efficient and effective use of administrative resources, support clear accountabilities, and streamline processes at the regional and local levels (e.g., reporting

relationships, funding and human resource accountabilities, common medical records, etc.).

The Committee believes that all existing and new centres should move towards greater integration of cancer services into one program. This includes such things as the establishment of a joint oncology program, single leadership for an integrated oncology program, support staff provided by the host hospital, and the development of annual joint operating plans for the integrated program.

The Committee recognises that greater integration of the regional centres with the host hospitals is only be a transition step towards total integration of cancer services in the hospital. In such instances, oncology could be a hospital division with its own management, separate bylaws and protected funding, and governed by a Board committee dedicated to oncology. Although the Committee believes that this would result in a high degree of integration, this concept needs to be re-examined in the future when the system has achieved a greater degree of equilibrium.

The Committee recommends that:

R7 **As a transition step towards greater integration, all existing and new regional cancer centres move towards greater integration of cancer services into one program with host hospitals. This includes establishing a joint oncology program, having single leadership for the integrated oncology program, having joint support staff, and developing annual joint operating plans for the integrated program.**

Tools to Support the Governance and Management Model

A number of key tools are needed to ensure that the Committee's governance and management model will be successfully implemented.

One, hospitals must commit strong support to providing cancer services and recognising cancer as a priority program. This will require vision, a strong and determined management, and staff buy-in. Most importantly, hospital governors should approve appropriate resource allocation strategies, and managers should measure and report on the operationalisation of these strategies.

Two, there must be strong support for developing the regions. This includes a willingness on CCO's part to encourage and develop the regional bodies, and enhance the responsibilities of the regional centres. This involves a shift in focus for CCO where its primary responsibility becomes a provincial overseer that ensures the smooth functioning of regional networks, and its secondary responsibility overseeing the management of certain services.

Three, there must be clarity about the roles and responsibilities of CCO and the regional bodies (see Appendix H). Support is needed from the Ministry to ensure this information

is communicated to and understood by all stakeholders. In addition, clear reporting requirements must be identified for the provincial, regional and local levels. At the provincial level, CCO should develop an annual accountability report to the public on the provincial cancer services system. At the regional level, regional bodies are accountable to the people in the regional, to the providers and to CCO. Regional bodies should develop annual accountability reports to their regions.

Four, the boundaries of the cancer regions must be defined according to recognised criteria. These may include geography, critical mass and/or levels of services. There should be one regional board for each region. In certain regions, there may be more than one regional centre which will require joint leadership of the regional body.

Five, changes in legislation are recommended to ensure that CCO is clearly responsible for advising on standards and quality of all cancer services in the province. The legislation should include the provision for the appointment of a supervisor in the event that CCO is not meeting its responsibilities as set out in legislation.

Finally and most critical, information systems and funding arrangements such as volume-complexity funding are required to support services and quality standards at the local, regional and provincial levels. These are addressed in greater detail in the following chapters.

The Committee recommends that:

R8 **The following be put in place to support the proposed governance and management model for cancer services: i) strong support from hospitals to provide cancer services as a priority program; ii) strong support from CCO for developing the regions; iii) development of a clear mandate, authorities, accountabilities and reporting requirements for the provincial, regional and local levels with Ministry support and stakeholder acceptance of these definitions; and iv) changes in legislation to ensure that CCO is clearly responsible for advising on standards and quality of all cancer services in the province. (This should include the provision for appointment of a supervisor in the event that CCO is not meeting its responsibilities as set out in legislation).**

5. BEST PRACTICES AND QUALITY OUTCOMES

BACKGROUND

Best practices and quality outcomes from a clinical perspective assume the consistent use of well-developed standards, guidelines, care pathways and excellent clinical judgement. From a system performance perspective, best practices and quality outcomes assume such things as the use of population-based targets, integration mechanisms, and indicators of accessibility and outcome. Both clinical and system performance assessments help identify where excellent care is being provided, highlight critical problems and pressure points, and can be used to track changes over time to see if improvements have been made.

CCO has a number of initiatives that help support best practices and quality outcomes in clinical care. The Program in Evidence-Based Care established in 1997, uses research results to influence practice by developing evidence-based clinical practice guidelines within 12 Disease Site Groups. Teams made up of health care providers, community representatives and researchers select and review the best and most relevant studies, synthesise relevant research information, obtain input from specialists and make recommendations for cancer care. The groups also develop evidence summaries on clinical topics where there is insufficient evidence to develop a practice guideline. Guidelines and summaries are distributed to clinicians and planners. To date, 50 guidelines and summaries have been developed (see Appendix I). In total, $.8 million of CCO's budget is allocated to support the Program (2000/01).

CCO's Quality of Care and Ethics Committee is responsible for the development of performance indicators at the provincial level and the regional/divisional levels. The committee oversees quality breakthrough projects, the results of which are shared with CCO's regional centres and its partners. Currently, the committee is initiating a pilot project to standardise the way centres report medical incidents.

In addition to CCO's initiatives, each individual regional centre and individual hospitals that provide cancer services have best practices and quality initiatives as part of their internal quality improvement programs.

From a system performance perspective, CCO collects some indicators such as population-based minimum target rates for cancer procedures that are used to determine human resources and service requirements.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

The Committee reflected on its knowledge of best practices and quality outcomes in Ontario's cancer services system.

All caregivers have access to information related to their profession. Information is obtained by scanning web sites, reading professional journals, attending national and international meetings, and through local discussions with peers, associates and drug companies. Patients assume that they will get optimal care based on the latest best evidence, receive the best care plan, and get the same care as patients who have the same diagnosis regardless of where they live. This does not appear to be the case.

Access to care and outcomes can vary significantly from centre to centre. Contributing factors include the lack of sufficient resources to support professional practices, the lack of and inconsistent use of available standards, guidelines and optimal care plans, the lack of audits, and differences in provider proficiency. For example, a recent retrospective study of pancreatic resection for cancer in Ontario showed that the likelihood of post-operative death was significantly higher in hospitals that had low or medium volumes of the procedure compared to hospitals with high volumes of the procedure.[29] The degree to which specialist surgeons confine the bulk or all of their practice to oncology varies significantly in Ontario. Once a surgeon is certified in a specialty, he or she can perform all cancer surgery regardless of its complexity or appropriateness.

All care programs should be designed to help caregivers avoid mistakes. The emphasis is not on blaming the caregiver who made the error but on examining the particular component of the system that allowed such an error to occur. There is no Ontario-wide program in cancer treatment to audit both medical and system errors (e.g., wrong side surgery, radiation field errors, drug choice or dosage errors).

In keeping with patient-focused care, members of the public should be aware that their risk of death and other outcomes following treatment for certain diseases are different from hospital to hospital. Every cancer patient in Ontario should have the assurance that he or she is receiving optimal care in an institution with a public track record of optimal outcomes for that specific disease.

The issue of waiting times is an important indicator of best practices and quality outcomes for the system. Cancer patients have to navigate a series of waiting periods related to each step in their diagnosis and treatment. One of the goals of coordinating care is minimising patients having to repeat certain processes as they move through the continuum of care. The patient should pass through a single program of care rather than a disjointed series of events provided by relatively independent groups of care givers.

The duration of waiting lists is one measure of efficiency of patient care and is a key element of assessing quality care. Bottlenecks increase waiting times and indicate which component, in the chain of diagnosis and treatment, is sub-optimal. For example, the management of patients during specific encounters includes waiting to have blood taken and tested, waiting to see a physician and waiting to receive chemotherapy. The perception is that patients move through this process more quickly in some institutions

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[29] Marko Simunovic et al., "Relation between hospital surgical volume and outcome for pancreatic resection for neoplasm in a publicly funded health care system," Canadian Medical Association Journal 160 (5), March 9, 1999. Pp. 643-8.

than in others. It would appear that a significant determinant is the degree to which an institution puts the emphasis on patient-centred care. It must be recognised that there is a difference between internal waiting lists that can result from inefficient care processes, and external waiting lists that are related to the imbalance between supply and demand.

In recent years, attention has focussed on the wait for radiation therapy. As well, recent studies have suggested that cancer surgery waiting times may be exceeding best practice. It is a challenge to define when waiting begins and ends at each stage, but it can and should be done. A consensus of experts is usually required to determine the maximum time that a patient can wait and still be assured of timely quality care. There is an urgent need to agree on definitions throughout the province, and to capture the data electronically to allow analyses of waiting lists at appropriate time intervals in each region. This surveillance should be a prime function of CCO which in turn can advise the appropriate regions and the Ministry, and suggest remedies.

The goal of CCO's Program in Evidence-Based Care and the Quality of Care and Ethics Committee is to promote best clinical practices and quality outcomes throughout the province and the regions. The regional cancer centres, and the teaching and community hospitals also attempt to promote best practices and quality outcomes at the regional and local levels.

Although anecdotal evidence suggests that these provincial, regional and local initiatives have improved the quality of clinical care and patient movement in certain instances (e.g., systemic therapy), there is less compelling evidence to indicate that they have advanced widespread best practices and quality outcomes in cancer care at the clinical and health system levels. There are a number of reasons for this.

One, the development of standards and guidelines requires time, administrative support, and clinical, research and administrative expertise. Although the clinical guidelines that have been developed through the Program in Evidence-Based Care are excellent, a concerted effort to develop a comprehensive range of guidelines has been hampered by the availability of resources. There are notable gaps in certain areas. For example, there are wide variations in surgical practice across the province as well as the perception of different standards of care. These variations in practice are due to the lack of provincial evidence-based surgical standards.

Two, although much effort goes into the development of clinical standards and guidelines, less effort has gone into ongoing communications about these tools and training and peer consultation opportunities on the appropriate and effective use of these tools. The extent to which provincially-developed standards are being used to improve local practice is unclear. Ideally, these guidelines should be incorporated into computerised patient care management systems to enable easy access when clinical decisions are being made.

Three, a formal performance improvement process does not exist that includes monitoring and assessing clinical and health system performance, providing feedback on where improvements are needed, and following up to ensure that changes in clinical and

system performance have occurred. Although the intent of the guidelines and standards is clear, and their quality excellent, the lack of audit feedback stands in the way of determining whether the program is having an impact. It is recognised that province-wide data are needed to support this process and inform providers and the public about performance.

The Committee believes that an ad hoc approach will not result in best practices and quality outcomes in cancer services, rather a concerted effort must be made to develop a systematic approach to improve *both* clinical and health system efficiency and performance.

CCO has a critical role to play in achieving best practices and quality outcomes in all of cancer care. The Committee believes that an enhanced focus within CCO should be established in the form of a Cancer Quality Council. The Council would provide central leadership and promote the active participation of the regions and local communities in achieving its goals. The Council should invite the participation of researchers and other experts from such organisations as the Institute for Clinical Evaluative Sciences and the Cardiac Care Network of Ontario. The Council will ensure that quality programs are in place, and best practices and quality outcomes in clinical and health system performance are achieved at all levels.

The Committee recommends that:

R9 A Cancer Quality Council be established within Cancer Care Ontario with the purpose of monitoring, assessing and improving the clinical and health system performance of all cancer services in Ontario. These services include health promotion and disease prevention, screening and early detection, primary care, diagnosis, treatment, rehabilitation, home/community care, palliative and supportive care.

The Cancer Quality Council will have a number of key ongoing activities. The Council will:

1. Oversee the development of evidence-based guidelines, care pathways and where appropriate, standards for clinical performance, using a data-based, consensus-driven approach. In addition, the Council will develop indicators for health system performance including measures of regional integration, access, network functioning, system effectiveness and cost effectiveness. The Council will develop an action plan within available resources that sets out clear deliverables and timelines for the systematic development of guidelines, care pathways, standards and performance indicators.

2. Develop an implementation strategy to support the successful implementation of these tools. The strategy should include ongoing communications, training and peer consultation opportunities, and ready access to guidelines where care is provided.

3. Develop and maintain a performance improvement process that includes ongoing monitoring of key activities, assessing performance, providing feedback on where improvements need to be made and incorporating follow-up. The improvement process will help identify critical problems and pressure points before they become crises (e.g., this includes the lack of human, financial, capital and operating resources). The process will also help target efforts on quality performance improvements and error prevention at the regional and local levels. The Council should pursue strategies to link quality and performance improvements with funding for services.

4. Ensure that the results of performance assessments are evaluated and compiled centrally. This should be done by an external expert body such as the Institute for Clinical Evaluative Sciences or by such a body in partnership with CCO. These results should be communicated to the public and providers through annual public accountability reports and other means (e.g., ongoing updates available on web sites, publications).

The Committee recommends that:

R10 The Cancer Quality Council have four key responsibilities: i) Oversee the development of evidence-based guidelines, care pathways, standards and performance indicators using a systematic approach that includes an action plan with clear deliverables and timelines for the development of these tools; ii) Develop a strategy to support the successful implementation of these tools at the regional and local levels; iii) Develop and maintain a performance improvement process that includes monitoring, implementing and follow-up, targets quality performance improvements and the prevention of medical and system-errors, and identifies problem areas before they become crises; and iv) Ensure that the results of performance assessments are evaluated and compiled centrally either by an external expert body or by such a body in partnership with Cancer Care Ontario. The results should be communicated to the public and providers through annual accountability reports and other methods.

The Cancer Quality Council will need access to data systems and information to support its work. This is addressed in the chapter, *Information*.

6. FUNDING

BACKGROUND

Funding to Support Cancer Care

In 1991/92, it was estimated that the total Ministry investment in cancer services in Ontario was $1.3 billion.[30] Of this money, the largest proportion – 77% – was used for treatment which included curative and palliative care (Table 9).

Ministry staff have estimated that the $1.3 billion expenditure on cancer ten years ago, has increased to about $1.5 billion in 2001/02. Staff have also concluded that the proportionate distribution of expenditures has stayed the same.

Table 9: Estimated Cancer-related Expenditure, 1991/92

Treatment Cure/Palliative	77.2%
Support/Rehabilitation	13.3%
Detection/Diagnosis	5.6%
Research/Evaluation and Administration	1.5%
Capital	1.3%
Prevention	0.7%
Education	0.4%

Source: Ontario Ministry of Health. *Life to Gain: A Cancer Strategy for Ontario*, April 1994.

It is difficult to track cancer expenditures in the province. Funding to hospitals and community-based agencies does not identify cancer-related services as a separate line item. The proportion of a hospital's budget allocated to cancer care (diagnostics, surgery, systemic therapy, rehabilitation, palliative care) is determined by each individual facility. As well, the proportion of a community care access centre's budget used for cancer-related care in the community is neither stipulated nor tracked.

It is easier to identify and track cancer expenditures in two specific areas – Ministry investments in CCO and radiation services. In 2000/01, CCO had revenues of $284.4 million of which $244.6 million came from the Ministry.[31] From 1994/95 to 2001/02, Ministry funding to CCO's base budget for the delivery of programs and services to cancer patients increased 70.6% or about 10% per year. In particular, a substantial funding increase occurred in CCO's radiation treatment program from 1998/99 to 2000/01. CCO received a 35% increase in this area from a base of $44.9 million to $61.9 million.

In February 1999, the Ministry agreed to reimburse CCO and PMH for radiation services on a cost per case basis. Currently, the Ministry pays $3,000 per case for radiation for a total of $71 million to CCO and $26 million to PMH. The Ministry has also provided CCO and PMH with one-time funding for targeted initiatives, funding for capital expansions and equipment, and funding to CCO to refer cancer patients to other Ontario cancer centres and the US (see Appendix J).

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[30] Ministry of Health, *Life to Gain: A Cancer Strategy for Ontario,* April 1994.

[31] Other sources of funds included private donations ($4.7 million), investment income ($4.5 million), research grants ($3.5 million), other grants ($16.1 million) and other income ($11 million).

CCO is accountable to the Ministry for its expenditures and for maintaining a balanced budget. Both CCO's legislation and MOU provide for annual audits by the Provincial Auditor or another auditor designated by the Lieutenant Governor in Council.

Hospitals and community-based agencies are also accountable to the Ministry for maintaining balanced budgets. Since cancer-related funds are not specifically identified in hospital, community and other primary care budgets, there are no specific audits for the use of funds for cancer-related services. Currently, there is no cost per case funding for cancer surgery nor a consistent funding approach for all of systemic therapy.

Funding to Support Physician Services

Physicians who provide cancer-related services are funded in a variety of ways.

- Radiation and medical oncologists working at the regional centres are employees of CCO and are supported with the Ministry's cost per case funding allocation for radiation, an operating budget for medical oncology, and fee-for-service income for both. Radiation oncologists at PMH are paid through the hospital using the Ministry's cost per case allocation.
- Paediatric and gynaecological oncologists have an alternate funding arrangement with the Ministry under the Alternate Payment Program. CCO receives some funds to cover administrative services for the gynaecological oncologists.
- All other cancer-related physician services are funded on a fee-for-service basis or through an agreement with the hospital where the physician is practising. For example, physicians at Kingston General Hospital are funded through the South East Academic Medical Organisation (SEAMO).

Currently, negotiations are being held to develop an alternate funding arrangement between the Ministry and radiation and medical oncologists. If successful, radiation oncologists would no longer be reimbursed through the cost per case allocation.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

Funding to Support Cancer Care

The Committee relied on a 1991/92 estimate of the total cancer expenditures in Ontario with more recent data available in a few notable areas. As a result, the Committee made the following conclusions:

- The Ministry needs to have current, valid and reliable information on the level of funding for all cancer services in the province. This is especially important for public accountability.
- Although current and detailed expenditures were available for CCO and radiation, these two areas reflect a relatively small proportion of the total funding for the cancer

services system. Compared to the estimated $1.5 billion spent on cancer services in the province, CCO accounts for only about 16% of the total Ministry investment.

- Although CCO has been successful in obtaining substantial funding increases for radiation services and the New Drug Funding Program, these increases support a relatively small proportion of all the cancer activity in the province. Increases to meet the growing demand for cancer services provided in hospitals, community-based agencies and cancer centres have been absorbed within the global budgets of these organisations.

As recommended earlier (Recommendation 2), the Ministry needs to recognise that all of cancer services constitute a priority program. In addition, the Committee believes that a comprehensive and consistent funding approach must be developed for cancer services in the province. The key components of this approach are a well-defined envelope of funds that are protected for cancer services, and an allocation methodology that incorporates volume, complexity and quality factors. These components would ensure that cancer services are a recognised priority with a clearly defined funding envelope that is not subject to organisation-specific priority setting exercises.

The importance of volume funding for maintaining service levels is illustrated in the following example. In Ontario hospitals, summer months and the year-end holiday season are characterised by significant decreases in the number of operations performed. This helps hospitals balance their budgets. A noticeable exception is cardiac surgery case loads which continue largely due to volume-complexity funding of cardiac cases. The Ministry pays hospitals on a case-by-case basis for cardiac surgery on the advice of the Cardiac Care Network. Annual targets are set and hospitals typically give cardiac preferential access to the operating rooms.

The Committee believes that cancer services should be funded in a similar manner. Hospitals providing cancer services in a region would essentially receive financial incentives through volume funding to prioritise their cancer services.

It is recognised that defining the envelope and the supporting methodology are complex and will need to be done in stages. The Committee believes that identifying the envelope should begin with in- and out-patient services for radiation (volume funding already exists for this procedure), followed by cancer surgery, systemic therapy, pathology and diagnostic imaging. Eventually, the other components of the continuum should be included in the envelope. It may also be prudent to begin with volume funding followed by refinements for complexity, which would then be linked to quality standards. CCO should consult with its stakeholders and advise the Ministry on the best way to proceed.

There is an opportunity to use incentives to support timely and accurate submission of information to CCO. If funding is tied to accurate reporting of clinical information for management purposes, the quality of cancer data will improve substantially.

The Committee recommends that:

R11 The Ministry of Health and Long-Term Care, on the advice of Cancer Care Ontario and others, develop a comprehensive and consistent funding approach for cancer services in the province that includes: i) an envelope of funds that are protected for cancer services; and ii) an allocation methodology that incorporates volume, complexity and quality factors.

Envelope funding for cancer will have an impact on where certain services are provided. For example, larger hospitals might be volume-funded for certain high-end surgeries that would be concentrated into fewer centres. Correspondingly, simpler surgeries would be provided "closer to home". It is recognised that these shifts will be difficult because of the financial implications for hospitals and fee-for-service providers. However, there is evidence to suggest that outcomes of complex surgical procedures are superior in high volume centres compared to centres performing occasional procedures. The reason is multifactorial and appears to be the result of increased expertise of nursing, ICU, anaesthesia and surgical staff. CCO should bring the stakeholders together to identify the issues and advise the Ministry on the best way to proceed.

Envelope funding for cancer services will make it easier to have accountability structures that ensure cancer-related funds are used appropriately. These structures should be at the local, regional and provincial levels.

The Committee recommends that:

R12 The Ministry of Health and Long-Term Care develop processes to monitor accountability for the funds allocated for cancer-related services at the local, regional and provincial levels.

Funding to Support Physician Services

The fee-for-service system compensates physicians at a consistent rate regardless of the complexity of, and the time that they spend on, a case. As a result, fee-for-service is not flexible enough to meet the increasing demands on physicians' time. These demands are due to the rapid growth in the incidence of disease, the increasing complexity of treatments that require more time to provide care, and the move towards integrated care with the expectation that physicians will be more involved in peer consultations. Alternate payment mechanisms are more sensitive to these variable demands. Since cancer care presents many challenges on physicians' time, the Committee believes that cancer services provided by physicians should be appropriately compensated through the use of alternate payment mechanisms.

The Committee recommends that:

R13 The Ministry of Health and Long-Term Care develop alternate funding mechanisms for physicians who provide cancer services.

7. INFORMATION

BACKGROUND

Cancer Care Ontario maintains the Ontario Cancer Registry (OCR) which is a computerized database of information on all Ontario residents newly diagnosed with cancer [32] or who have died of cancer. All records except pathology reports are coded at the source and provided to the OCR in electronic form. Paper copies of pathology reports are sent to the OCR by hospital and private pathology laboratories, and are coded and entered by OCR staff into a computerised database. CCO also monitors radiation waiting lists.

At the individual patient level, information is collected by each CCO regional centre that provides cancer-related services. For example, each regional centre collects information on patients who receive radiation or systemic therapy. This information is then collected and summarised by CCO. All other facilities that provide cancer surgery, radiation (PMH) or systemic therapy collect patient information using their respective data systems. Currently, this information is not available to CCO. Usually a patient who gets cancer services from a CCO-regional centre and its host hospital or another hospital has two separate health records. This impairs the delivery of integrated cancer care across all treatment modalities. A patient's information does not move with him or her. PMH has the highest level of integration of patient information on cancer care. A single electronic record includes all cancer treatments (surgery, radiation, systemic therapy) as well as any other care received by the patient.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

Dr. Michael Guerriere, an information consultant to the Committee, reviewed the federal, provincial and local information management situation with the Committee. The Committee came to the conclusion that the current information management system for cancer services is fragmented and has some key limitations:

- A consistent *clinical* information system that focuses on the patient does not exist. Such a system would provide data from the time of diagnosis onward, and would support practice review, peer comparisons and research into best practices.
- A provincial *management* information system that focuses on the performance of individual as well as groups of institutions does not exist. This system would support effective and efficient management processes, and research into best management practices.
- An integrated electronic record that links the broad range of cancer care provided at the local level does not exist in most parts of the province. PMH is the exception. Such a record would improve coordination of care, ease referrals and support communications between clinicians.

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[32] Except for non-melanoma skin cancer.

The Committee believes that information management (IM) is the backbone for an integrated cancer services system. It is also critical to support CCO's advisory role and the various research efforts in the province.

It is recognised that developing a comprehensive and useful IM system is complex, and can be overwhelming, resource-intensive and very time-consuming. This is especially true when the goal is to integrate information that is collected by a wide range of different providers.

The Committee concluded that a critical first step is to ensure that a comprehensive information strategy is developed for cancer services that includes a provincial *management* information system, a *clinical* information system, and a regionally-integrated patient record. The strategy should also recognise the need for information to support research. The strategy should be championed by leadership at the senior level at CCO, include the active participation of the broad range of cancer providers, and be supported with appropriate expertise and resources. Realistically, there are limitations to available resources. As a result, the strategy must be clearly articulated, well developed, doable, and incorporate manageable steps that gradually build a comprehensive system. It should identify clear priorities for action, and identify key deliverables and target dates for completion.

Expectations for developing an IM system for cancer care should be set at a reasonable level. For example, it will probably take five or more years to develop integrated electronic records to support care delivery. As well, it must be recognised that IM expenditures will have to reach 5-6% of total spending on care delivery before integrated systems are likely to develop. To sustain momentum, it is important to have early wins and build on successes. Well-defined projects that systematically develop the necessary information systems should be kept manageable (e.g., projects should be completed in less than 18 months). As well, progress can be achieved more quickly if certain conditions are put in place. For example, development of management and registry information systems can be accomplished more quickly if data submission is tied to funding.

The following should be included in the strategy:

One, the strategy should capitalise on available expertise, use effective and efficient means to achieve goals, and seek efficiencies through joint ventures and contracting arrangements. For example, software development is costly and time consuming. Effective and less costly alternatives such as off-the-shelf software should be used, wherever possible.

Two, it must be recognised that management and clinical information systems are different, and require different approaches:

- To further the development of a *management* information system, the focus should be on collecting data components across the entire system of cancer service providers. This will help achieve early benefits such as management reports on services and access. This information will support CCO's advisory role. (Precedent exists for this approach with the Cardiac Care Network of Ontario, which has been highly successful in monitoring and influencing institution and system performance.)

- To further the development of a *clinical* information system, steps to achieve clinical integration should focus on more in-depth attempts using a few pilot sites. Care must be taken that these pilots have clearly defined deliverables and deadlines, and that effective processes are put in place that translate the results of the pilots to other sites and the whole system, as expeditiously as possible.

- To further the development of regionally-integrated electronic records and integrated systems in general, regional cancer centres should build on the information systems of the host hospitals. For example, regional centres could purchase IT support and management from their respective host hospitals.

Three, data that are required to support cancer research should be identified. A critical piece is the development of a fully-linked comprehensive data set. Currently, various pieces of the "cancer picture" are in various places – the Cancer Registry, the Canadian Institute for Health Information, the Institute for Clinical Evaluative Sciences, the Ontario Health Insurance Plan, the Radiation Oncology Research Unit, in pathology reports and the drug program. No one has the total picture nor is there the ability to link the pieces to create the total picture.

Four, the IM strategy must address confidentiality and privacy concerns. For example, an integrated electronic patient record raises complex legal issue that should be addressed through comprehensive health information legislation.

Five, the strategy should include the following key areas as part of centralised efforts to develop a cancer information system:

- As a first step, a centralised inventory should be developed that identifies the cancer systems that are currently being used by providers in the province. Since cancer information needs to be integrated from multiple providers, an inventory will help facilitate and guide the move towards integration. For example, it is essential that data elements, terminology, scoring system and so on be uniform for the regional centres, PMH and all other providers. This will enable CCO to analyse provincial activity and fulfil its advisory role.

- Management and registry information should be assembled into a provincial database. Every hospital in the province should be required to send an electronic abstract to CCO for every patient encounter that relates to cancer. CCO should work through the Canadian Institute of Health Information (CIHI) to augment the existing abstracting system to add the data elements that CCO needs. This should be done gradually in

stages, beginning with a set of simple data elements and evolving into a more complex system over time. It would be useful to connect the data reporting process to funding (i.e., Ministry or CCO funding is not sent to the facilities until the complete abstract is received). Consideration should be given using available expertise by outsourcing this data collection process to CIHI.

- As noted in the chapter, *Best Practices and Quality Outcomes*, it is recommended that CCO's focus on quality be strengthened. CCO should maintain clinical protocols and best practice information in a central knowledge base, which should be widely available to *all* physicians via a web browser.

- Systems for chemotherapy administration are best managed centrally but should be integrated into the drug administration systems in every hospital. Stand-alone systems that are not linked have limited value. This integration of information could be used to generate additional management information.

- Systems to manage radiation therapy should be consolidated to achieve economies of scale. Centres that are large and well developed such as the larger regional centres and PMH/UHN could be contracted to manage the information needs of the smaller radiation therapy centres.

- Consideration should be given to contracting out or merging the IT function with a large information department that has been successful such as those at the University Health Network or Sunnybrook and Women's College Health Sciences Centre. This is in keeping with capitalising on available expertise and seeking effective and efficient ways to get the work done.

The Committee recognises that there are a number of key provincial and federal initiatives that can further the development of a cancer information system. A prime example is the Data Tracking, Referral and Analysis of Capacity for Cancer Care (D-TRACC). This provincial initiative is a comprehensive data tracking system linking all components of a cancer patient's treatment path. D-TRACC would include a patient's movement through the system from primary care to hospital to treatment to follow-up. This information would provide estimates of patient flow, and identify potential "bottlenecks" and resource requirements.

A second example is the provincial *Smart Systems for Health* project which might be helpful with connectivity and network infrastructure needs across the province. For cancer, this initiative might take over managing the network and messaging needs of CCO in the near term. Although the federal initiative, Canada Health Infoway Inc., is just getting started, it will likely invest in expanding existing systems that show significant promise in enhancing electronic patient records. An integration project involving host hospitals across the province might be successful in attracting funding.

The Committee recommends that:

R14 The Ministry of Health and Long-Term Care fund and work with Cancer Care Ontario and other stakeholders to implement a cancer information strategy that includes the systematic development of a provincial management information system, a clinical information system, a regionally-integrated electronic record at the local level, and a fully-linked comprehensive data set that can be used to support research. The strategy should establish priorities within available resources, incorporate manageable steps that gradually build a comprehensive system, involve key stakeholders, capitalise on available expertise, use effective and efficient means to achieve goals, and seek efficiencies through joint ventures and contracting arrangements.

Other Information Issues – System for Staging and Uniform Pathology Reporting

Staging System

The universally accepted system for staging is the Union Internationale Contre le Cancer (UICC), also known as the American Joint Commission on Staging. The system describes staging for 95% of all cancers (excluding such cancers as leukemia, lymphoma and brain tumours). There are two processes to staging: 1) collecting the medical information required to understand the extent of disease; and 2) analysing this information and assigning the stage. Typically the physician assigns the stage and uses this information to decide the best treatment. Currently, the process may take up to three weeks to complete since it involves obtaining the results of imaging investigations, operation reports, pathology reports, etc.

Pathologists have work loads that include the diagnostic review of a wide variety of tissues containing a wide variety of disease processes (including cancer). The efficiency and accuracy of reporting on cancer biopsies and specimens relies on a complex process that includes appropriate technical and human resources. Delay in specimen reporting is a significant cause for anxiety in a patient waiting to hear the results. A similar set of circumstances applies to the provision of imaging services.

Currently, the system is not recorded by all providers of cancer services in the province to stage their patients simply because it is not required information. The Committee believes that cancer staging should be used and recorded consistently by all providers. It should be part of the quality component of completing the in- or out-patient cancer record for all patients. Accurate staging is necessary to support funding decisions that are based on volume-complexity considerations. Staging data are also important to monitor waiting times, and flag instances where access to care may be jeopardised.

The Committee recommends that:

R15 The Union Internationale Contre le Cancer staging system be used consistently to stage all cancer patients in the province. In disease sites where the UICC stage is inappropriate or unavailable, experts from these disease sites should use a consensus approach to determine an acceptable disease staging system for implementation across Ontario.

Uniform Pathology Reporting

The Pathology Information Management System (PIMS) is a network connecting pathology labs in Ontario with the Ontario Cancer Registry. PIMS is being piloted in three labs. The system allows these labs to submit relevant information to the Registry in a more timely and efficient way, thereby replacing manually intensive tasks associated with searching, sorting and sending paper pathology reports to the Registry. Although PIMS has the capacity to improve information transfer, a critical issue remains – Ontario does not have a system of uniform pathology reporting.

A critical quality component for the cancer system is the development of synoptic pathology reports for each disease site. (There are best practice guidelines for what needs to be in a pathology report so all clinicians have the relevant information to guide decision-making. Templates for these reports are called *synoptic reports*.) Although synoptic reports are well-recognised, each group of pathologists would need to agree on the correct definitions for Ontario synoptic reporting. The standardised reports would then be incorporated into the clinical information system.

The Committee recommends that:

R16 A process and system be developed for uniform pathology reporting in Ontario.

8. HUMAN RESOURCES

BACKGROUND

Human Resources Recruitment and Retention Initiatives

There have been a number of provincial initiatives that have focused on cancer human resources.

- The Cancer Human Resources Committee, initiated by the Ministry of Health and Long-Term Care in 1999 and chaired by the Ministry, is made up of representatives from CCO, Princess Margaret, the Michener Institute for Applied Health Sciences, and the College of Medical Radiation Technologists of Ontario. It is a mechanism to monitor and recommend actions to increase the supply primarily of radiation treatment professionals. One initiative of the committee was a Radiation Therapy Think Tank, which made a number of recommendations for recruiting and retaining radiation therapists.

- In the late 1990s, CCO established a task force to identify immediate and long-term human resource requirements for radiation oncologists, radiation therapists and physicists, and to make recommendations on how to meet these requirements. The Report on the Task Force on Human Resources for Radiation Services was submitted to the Minister of Health and Long-Term Care in 1999.

- Since 1999, through its Radiation Treatment Staff Recruitment Program, CCO has aggressively recruited radiation professionals in Canada and beyond to address the human resources shortages in the province. The program has resulted in a net gain of 106 radiation therapists, 27 radiation oncologists and 10 medical physicists. Recruitment efforts are being expanded to include professionals in systemic therapy (chemotherapy and hormone therapy). The Royal College of Physicians and Surgeons of Canada and the College of Physicians and Surgeons of Ontario are assisting with the recruitment of oncologists by making changes to the requirements for licensure and certification.

There are many local initiatives to recruit and retain staff to provide cancer-related services. For example, individual facilities that are not managed by CCO recruit and retain staff such as medical and surgical oncologists, nurses, pharmacists and pharmacist technologists. In addition to these staff, PMH attempts to recruit and retain staff to support its radiation oncology program (e.g., radiation oncologists, radiation therapists and medical physicists). CCO, as an employer, also focuses efforts at recruiting and retaining staff such as nurses and pharmacists to support activities at its regional centres.

An important strategy for recruitment and retention of staff is supporting ongoing education needs of providers. There are many local initiatives that address these needs. For example, individual facilities support their staff through continuing education programs and conferences. CCO also provides continuing education opportunities for its

staff, and through the regional centres has provided continuing education opportunities for professionals in the region such as oncology nurses and pharmacists/pharmacist technicians.

Current Human Resources Situation

A large number of health care providers work in the cancer services system, although the exact number of institution- and community-based providers is unknown. Oncology was identified as a priority health program in the report of the Expert Panel on Health Professional Human Resources, which was released recently by the Ministry of Health and Long-Term Care (2000).

CCO is the employer of 2,300 staff most of whom work in the regional centres. In addition, medical and radiation oncologists at the regional centres are employed by CCO. CCO develops human resource policy and conducts labour relations for all of its staff. Regional centres and host hospitals that have joint venture agreements develop arrangements on how best to provide services using employees of two separate organisations. CCO has estimated that the regional cancer centres will require an additional 1,000 employees within five years, due to the increasing incidence of cancer, the growing complexity of treatment and advances in technology.[33]

In non-CCO-managed hospitals, staff are the employees of the individual hospitals. Medical staff have privileges at the hospital and either bill fee-for-service or negotiate other payment arrangements with the hospital.

In terms of community-based providers, it is unclear how many family physicians provide cancer-related care. Similarly, it is unclear how many staff contracted through community care access centres provide cancer-related care.

Unions and Associations

The union situation as it relates to cancer services is extremely complex. The same job may be unionised in one jurisdiction and not in another, or the same job may be represented by two different unions in different jurisdictions. A comparable job in an in-patient hospital setting and an out-patient CCO clinic setting in the same town may be represented by the same or different unions.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

A provincial human resource strategy to support the training, recruitment and retention of professionals to provide cancer services does not exist. Although CCO has developed a human resource strategy for cancer, the strategy mainly focuses on providers of radiation services. It does not address strategies for the broad range of other cancer-related professionals who work in institutions and the community throughout the province.

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[33] Cancer Care Ontario. "Building a cancer care workforce" *Cancer Care* Vol. 5 (2), Summer 2001.

Although local initiatives may be successful to a certain degree, they are not supported with a broader provincial framework. More importantly, without this broader framework, these local initiatives compete against each other for the same human and financial resources. A number of examples of specific human resource issues are presented.

Nurses play a critical role in patient care. The simple fact is that there are too few nurses available leading to calls to increase the number of training positions immediately. This is also the case for radiation therapists. Shortages of these professionals, as with nurses, have led to increased waiting lists, and cancelled procedures and treatments. Unfortunately, the decision to train more of these professionals will not provide an instant solution because of the length of training required.

Another example is anesthesia. Cancer operations in Ontario are being postponed because of an acute shortage of anesthetists. In previous years, the ability for fully qualified anesthetists to immigrate and work in Ontario was made difficult. While maintaining quality standards, this issue needs to be remedied immediately and a long-term solution to the anaesthesia problem urgently sought.

A final example is pathologists. Pathology results are critical for diagnosing cancer and proceeding with the appropriate treatment. About 50% of the average pathologist's time is spent dealing with cancer cases.[34] With the increasing incidence and prevalence of cancer, the increased sophistication of diagnostic techniques and more complex reporting requirements, the demands on the current supply of pathologists are going up drastically. Currently, Ontario is well below the Canadian average of pathologists per million population (26 per million compared to 35 per million in 2001– Figure 9. More alarmingly, indications are new graduates will not be able to replace the projected number of retirees (Table 10).

Table 10: Ontario Retirements And Newly Qualified Pathologists 2001/2025*

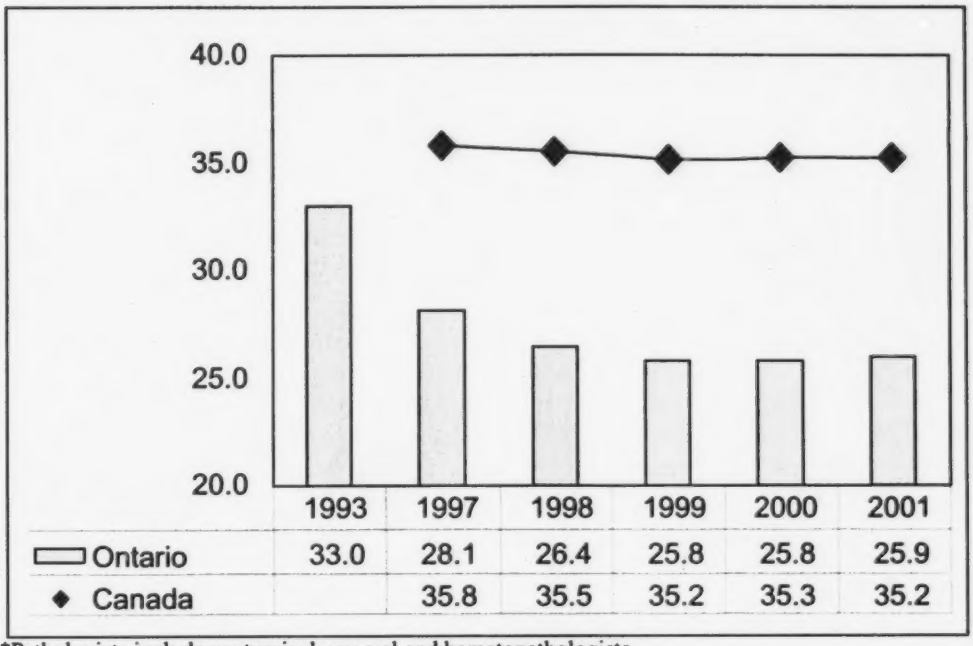
Years	Retirement	Graduates
2001-2005	29	24
2006-2010	35	
2011-2015	51	
2016-2020	62	
2021-2025	68	

*Pathologists include anatomical, general and hematopathologists.

Severe human resource shortages in cancer are a microcosm of issues in the broader health care system. The shortage of professionals such as nurses, radiation therapists, anesthetists and pathologists emphasises the interdependence of Ontario's cancer service and the overall human resource policies of the Ministry. Although CCO cannot be held responsible for resolving these issues, it can play a significant role in developing an overarching provincial strategy to support the training, recruitment and retention of a sufficient number of appropriately trained professionals to provide cancer services.

[34] Ontario Medical Association Laboratory Medicine Presentation to Dr. A. Hudson, December 17, 2001.

Figure 9: Ontario Pathologists per Million Population 1993/2002*



*Pathologists include anatomical, general and hematopathologists.

Although considerable progress has been made with radiation human resources, the need for a broader range of human resources for all cancer services must be addressed. A provincial strategy for cancer human resources should complement the Ministry's overall provincial human resource strategy for health, and incorporate regional and local approaches to attract and retain providers of cancer-related care. Input from the regions will identify regional human resource concerns, and a strong regional commitment will help operationalise the strategies at the local level.

The Ministry should ensure that there are an appropriate number of training spaces to support an adequate supply of the full range of cancer service providers required in the future. These spaces should be appropriately funded.

The Committee recommends that:

R17 Cancer Care Ontario continue to develop a provincial cancer human resource strategy to support the training, recruitment and retention of a sufficient number of appropriately trained professionals to provide the full range of cancer services. This strategy should complement the Ministry's overall provincial human resource strategy for health, and include regional and local approaches and initiatives to improve the recruitment and retention of these providers. In addition, the Ministry should ensure that there are an appropriate number of funded training spaces to support an adequate supply of the full range of cancer service providers required for the future.

When the Chair of the Committee met with a number of unions (see Appendix D), three key issues were identified:

- In general, the average seniority of in-patient workers is approximately ten years more than comparable out-patient workers.
- Unions feel that their out-patient workers have specific cancer-related skills. If out- and in-patient unions were merged, workers might be bumped into positions that might suit their overall skills but which might have no cancer content.
- Some unions expressed frustration that CCO has negotiated by site in some instances. These unions preferred the province-wide negotiating system that CCO employed with the Professional Institute of the Public Service of Canada (PIPSC).

The Committee examined models that would require merging of in- and out-patient unions, or would bring non-unionised and unionised groups together. Victor Pathe, a human resources consultant to the Committee, pointed to the significant human resource changes that arose from the hospital mergers directed by the Health Services Restructuring Commission. Human resource issues have been resolved but they did take a great deal of time and effort.

It is the view of the Committee that, at this time, the model that is being recommended will not have an effect on union/management or collective bargaining matters. When further integration efforts are contemplated in the future, it will be essential for human resource strategies to be fully developed as part of the overall planning.

9. PATIENT- AND PROVIDER-FOCUSED EDUCATION AND COMMUNICATION

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

Providers of cancer care must communicate effectively with one another and with their patients. From the patient's perspective, this communication leads to an integrated and co-ordinated care experience. As well, it leads to information about such things as likely complications of treatment or of danger signs that might prompt re-investigation or readmission. From the provider's perspective, this communication results in opportunities for peer support and the exchange of critical information that can improve care. It is recognised that informal communications already occur between providers. As well, formal networks have been established to try and bring together various groups of professionals (e.g., the Surgical Oncology Group). These groups have had varying degrees of success.

The perception is that there is a lack of communication between surgeons, radiation oncologists, medical oncologists and general practitioners, and between these providers and their patients. A number of strategies should be pursued to address this problem.

One is to support the continued professional development of health providers using a team and mentoring approach. Lifelong professional education is best achieved by learning while doing or "learning in practice", where the practice environment is designed to maintain and enhance professional competence in an ongoing and integrated way. For example, a shared care model that partners family physicians with providers of complex chemotherapy will enhance the practice and knowledge of family physicians, free up specialists' time to do more specialty care, improve timely access to care, and result in more co-ordinated patient care. It would also help build respect and collegiality between all providers and increase knowledge among providers of the total cancer services system.

The Committee recommends that:

R18 Cancer Care Ontario, in partnership with other stakeholders, develop initiatives to support the professional development of providers using team and mentoring approaches to care.

A second strategy is to strengthen ongoing communication between all providers of cancer services in the province and their patients. There are some initiatives in this area. For example, the Bayer Institute's Course in Clinician-Patient Communication is used widely in the regional centres and is starting to be used at PMH/UHN. The course is designed to enhance the four Es – engagement, empathy, education and enlistment – in clinician-patient communication.

Improved patient-provider communication reflects the Committee's aim of achieving quality care that supports the important role of patients and their families as participants in that care, that meets the needs of these individuals and upholds best practices.

The Committee recommends that:

R19 Cancer Care Ontario, in partnership with other stakeholders, develop a strategy that supports continuous communications between *all* providers of cancer services in the province and their patients.

A third strategy focuses on the patient. The experience of cancer can be overwhelming for patients and their families. Ironically, the situation is made more difficult by the overabundance and dearth of valid and reliable information. Typically, either patients do not get the information that they really need or they get totally confused by the information that they do get. This increases anxiety and confusion.

A number of key organisations such as the Canadian Cancer Society have a strong focus on helping patients make their way through the cancer services system. This includes providing accurate and timely information on such things as cancer prevention, the questions to ask when making decisions about care and treatment, and the services and resources that are available and how to obtain them.

It is well known that the patient must have sufficient information to give informed consent for diagnostic and therapeutic measures. This is particularly true for cancer patients when best practice may indicate alternative procedures each with its benefits and risks. It is vitally important that the patient truly understand the alternative paths and not be swayed by advice of a particular care giver who may derive either academic or financial benefit from a particular decision. This information should be sensitive to the diversity of individuals that are being served (e.g., different cultures, socioeconomic statuses, ages, genders and lifestyle choices). Information should be provided using traditional means of communication (e.g., printed brochures) as well as web-based technology (e.g., a patient suffering from prostate disease can go through an interactive computer program in which alternatives are described before informing the caregiver which procedure he will undergo).

The Committee believes that CCO should support and participate in the efforts of organisations such as the Canadian Cancer Society and others to educate patients about the cancer services system, and to provide information on available services and resources.

10. RESEARCH

BACKGROUND

Research Sites

Ontario has an international reputation for its cancer research which includes basic, translational and health services research. Research in Ontario is conducted by researchers affiliated with a wide range of organisations. Some of the most notable cancer research sites include:

- The five academic health science centres, their faculties of medicine and affiliated teaching hospitals play a key role in conducting health research.

- The Princess Margaret Hospital (University Health Network) conducts widespread cancer research through its Ontario Cancer Institute (OCI). OCI has six research divisions: cancer informatics; cellular and molecular biology; epidemiology, statistics and behavioural research; experimental therapeutics; medical physics; and structural and molecular biology. OCI has 68 scientists including 11 clinician scientists. The average amount of peer review funding for each investigator is $328,456 for an estimated total of over $22 million in current research grants.

- Cancer Care Ontario supports a number of research programs such as the Radiation Oncology Research Unit, the Research Unit in the Division of Preventive Oncology, the Ontario Clinical Oncology Group, the Ontario Cancer Genetics Network, and the Program in Evidence-Based Care (see Appendix E). CCO's actual budget for research in 2000/01 was $2.1 million from operating, $4.7 million from non-operating (grants) and $4.5 million from CCO reserves.

- The Institute for Clinical Evaluative Sciences is an independent research institute whose mandate is to evaluate the effectiveness, efficiency and equity of health care in Ontario. Funded by the Ministry, ICES houses a rich database of clinical and administrative data that provides information about the health care of all Ontarians, under strict conditions of privacy and confidentiality. ICES disseminates its research through a number of venues including provincial "atlases" that describe variations in care and outcomes for a variety of diseases. A number of ICES' reports deal with the care of cancer patients.

Research Funding

Research funding comes from a number of sources. The majority of funds are awarded by international, national, provincial and local agencies after a highly competitive review process. Funds are also obtained from industry particularly for clinical trails. It is essential that ownership of intellectual property be defined in detail before research prospects are undertaken.

A major source of funds is the Canadian Cancer Society which flows money to the National Cancer Institute of Canada (NCIC) to allocate for cancer research. The NCIC is the largest funder of cancer research in Canada, having allocated $60 million in the past year. All funds come from public donations – $42 million from the Canadian Cancer Society and $18 million from the Terry Fox Run. About 57% of research funds from NCIC go to Ontario researchers.

Another source of funds is the Canadian Institute for Health Research which has a Cancer Institute and supports research in the area. As well, Ontario recently announced the establishment of the Ontario Cancer Research Network. The Ministry of Health and Long-Term Care announced the Network in December 2000, with $50 million allocated for its development and research operations. The vision of the Network is for Ontario to be a world leader in translational cancer research. The goals of the Network are to: i) provide infrastructure so that the number of patients entering clinical trials in Ontario will double over three years; 2) provide research funds to speed translation of research into new therapies; 3) create an information network linking cancer centres, researchers and patients; 4) create a tumour bank network; and 5) enhance research possibilities of clinical studies. The success of the Network depends on enhancing the current strong cancer research system in Ontario, and strengthening the interactions and cooperation among the entire cancer care community and the broad health research community.

Finally, a major national effort is underway to create and implement a cancer control strategy that includes a strong research component. The strategy is being developed by Health Canada, the National Cancer Institute of Canada, the Canadian Institutes of Health Research and the Canadian Association of Provincial Cancer Agencies, and is expected in December 2001.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

The Committee believes that Ontario researchers are making important and significant contributions to advancements in the quality, outcomes and access to cancer care. It is clear, however, that research is costly and complex. For example, there is clear evidence that earliest detection and institution of appropriate therapy are related to longer survival in some cancers. This concept is fundamental to the major strategy for cancer control. Unfortunately even under these optimal conditions, some patients succumb whereas others diagnosed and treated late do well. This leads to a critical research question: what is the factor that is the main determinant of outcome? The evidence primarily points to the inherent aggressiveness of the particular tumour in a particular patient.

Research efforts are being directed more and more at studying the specific identifiers in the DNA of cancer cells that control the aggressiveness of certain tumours in patients, their susceptibility to early spread, sensitivity to radiotherapy, or susceptibility to drug treatment. Ultimately, it is hoped that a DNA "fingerprint" can be obtained of each patient's specific tumour cells so that therapy can be individualised.

This kind of research is very costly and currently is best carried out by well-funded, large groups or consortia of groups of experts. It is unlikely although not impossible that small research units will make much progress in cancer gene research. Units unable to concentrate the critical mass of people, machinery and dollars are more likely to contribute in other important areas such as clinical trials.

It is critical to maintain the ongoing financial support of agencies such as the Canadian Cancer Society, the National Cancer Institute of Canada and the Terry Fox Run. The establishment of the proposed Ontario Cancer Research Network will help ensure that the strong programs of cancer research in the province continues, that research results are translated into improved patient care as quickly as possible, and that the public is made aware of new treatments. The national cancer control strategy will also support the important role of research.

It is critical that the Ministry, through its support of the Ontario Cancer Research Network and as part of the national cancer control strategy, continue to provide resources to support innovative research initiatives in cancer care. The Ministry should also challenge both levels of government – provincial and federal – to expand research funding. Innovative funding strategies should also be explored including funding incentives for clinical trials. With the increasing emphasis on integrating the broader continuum of care, integration research should also be considered. As noted in the chapter, *Information*, integration and other research will require the development of a fully-linked comprehensive database for cancer services.

The Committee recommends that:

R20 The Ministry of Health and Long-Term Care continue to provide resources to support an innovative program of research that maximises the development of evidence for best practices, improves approaches to patient care and fosters clinical trials. Research initiatives should be supported with innovative strategies such as funding incentives for clinical trials. The Ministry should also challenge both the provincial and federal levels of government to expand research funding.

11. NEW TECHNOLOGIES AND PHARMACEUTICALS

BACKGROUND

CCO administers the New Drug Funding Program as a provincial program on behalf of the Ministry. The Program is an evidence-based approach to introducing, and managing the use and costs of a variety of new and expensive drugs. The Program began in 1995 to fund paclitaxel for the treatment of a subset of patients with ovarian and breast cancer. Since then, the program has expanded to reimburse regional cancer centres and hospitals in Ontario for selected new expensive anti-cancer and supportive care drugs according to evidence-based practice guidelines. The guidelines are developed by CCO's Program in Evidence-Based Care. Currently, only intravenous (IV) drugs have been evaluated. The Policy Advisory Committee of the New Drug Funding Program recommends which drugs should be funded through the Program and the criteria for their approval. Only the most cost effective regimens are recommended. These drugs are administered in participating hospitals close to the patient's home. Reimbursement is based on the use of drugs according to evidence-based guidelines and specific criteria. CCO monitors utilisation.

In 1999/00, the program paid out $25.7 million, half of which went to regional cancer centres, their host hospitals and PMH. The remaining 50% was paid to about 80 other facilities. In the following year, the total program expenditure was $37.9 million which was used to fund 14 drugs for 24 different indications to treat an estimated 8,000 patients.

In 2000/01, CCO launched its Drug Formulary Program to help standardise systemic therapy delivery across the province and improve access to this treatment. The Program recommends acceptable combinations of drugs. It includes IV and oral drugs. Formulary drugs are not funded provincially (except for the ones under the New Drug Funding Program). Funding comes from the cancer centre or hospital drug budgets.

Innovations in diagnostic technology can be extremely expensive. Some of these technologies can be used for a variety of diagnostic procedures (e.g., positron emission technology or PET scanning) whereas others are cancer-specific. With the exception of new radiation equipment, hospitals fund new technologies from their global budgets, and may or may not obtain additional capital funding from the Ministry or through fundraising.

COMMITTEE'S OBSERVATIONS AND RECOMMENDATIONS

CCO plays an important role managing and administering the New Drug Funding Program. The Program has effectively incorporated an evidence-based approach to the use of drugs. As well, the program has helped achieve a more rational use of scarce dollars since new drugs are only given according to evidence-based protocols. This helps curb the prescribing of expensive drugs for non-protocol indications. Actual savings have not been quantified to date.

Managing the use of new high cost drugs under evidence-based protocols is viewed by hospitals and cancer centres as an effective way to ensure that patients have access to leading edge treatments regardless of geography. Since the program reimburses drug costs, small hospitals do not have to worry about covering the drug expenditure.

The Ministry is to be commended for supporting the program through CCO. Indeed, the Ministry should continue to work with CCO to expand the Program to ensure that the evidence-based approach to managing the cost of expensive drugs continues as new evidence develops. In addition, efforts should be made to quantify the cost savings. It must be recognised that drug costs are increasing at an alarming rate. It is critical for the Ministry to explore ways to keep the cost of these drugs to a minimum.

The Committee recommends that:

R21 The Ministry of Health and Long-Term Care continue to maintain the New Drug Funding Program through Cancer Care Ontario, and monitor the ongoing impact of this initiative. CCO should also maintain, expand and continuously update its Drug Formulary.

Until recently, the New Drug Funding program has only evaluated IV drugs. CCO has begun to prepare evidence-based guidelines on oral agents and forward them along with recommendations of the Provincial Policy Advisory Committee (of the New Drug Funding Program) to the Ontario Drug Benefit Program. CCO has begun to evaluate new and existing diagnostic and non-drug therapeutic technologies. It is recognised that CCO can benefit from national and international initiatives in these areas. CCO should have a process in place to evaluate these modalities, either directly or indirectly by assessing evaluations that have been done by others. CCO should then advise the Ministry on whether to fund and/or purchase these drugs and technologies, and where they should be offered and/or sited.

The Committee recommends that:

R22 Cancer Care Ontario, in partnership with other stakeholders, participate in ongoing evaluations of new and existing technologies, and anti-cancer and supportive drugs. Based on the results of these evaluations, CCO should advise the Ministry of Health and Long-Term Care on whether to fund and/or purchase these drugs and technologies, and where they should be offered and/or sited.

PART THREE: CONCLUSION AND RECOMMENDATIONS

CONCLUSION

Ontarians receive cancer care from many dedicated providers in a wide variety of settings. The primary focus of the Committee's discussions was to improve how that care is provided to patients. This was reflected in the Committee's vision for the cancer services system – All Ontarians will have timely and equitable access to comprehensive and integrated quality cancer services.

The cancer services system is characterised by many governors and managers who oversee pieces of the system. In addition, CCO as the principal advisor to the Minister on cancer care has had variable success in fulfilling its role, especially as it relates to advocating for the entire cancer services system.

It became clear over the course of the Committee's work that:

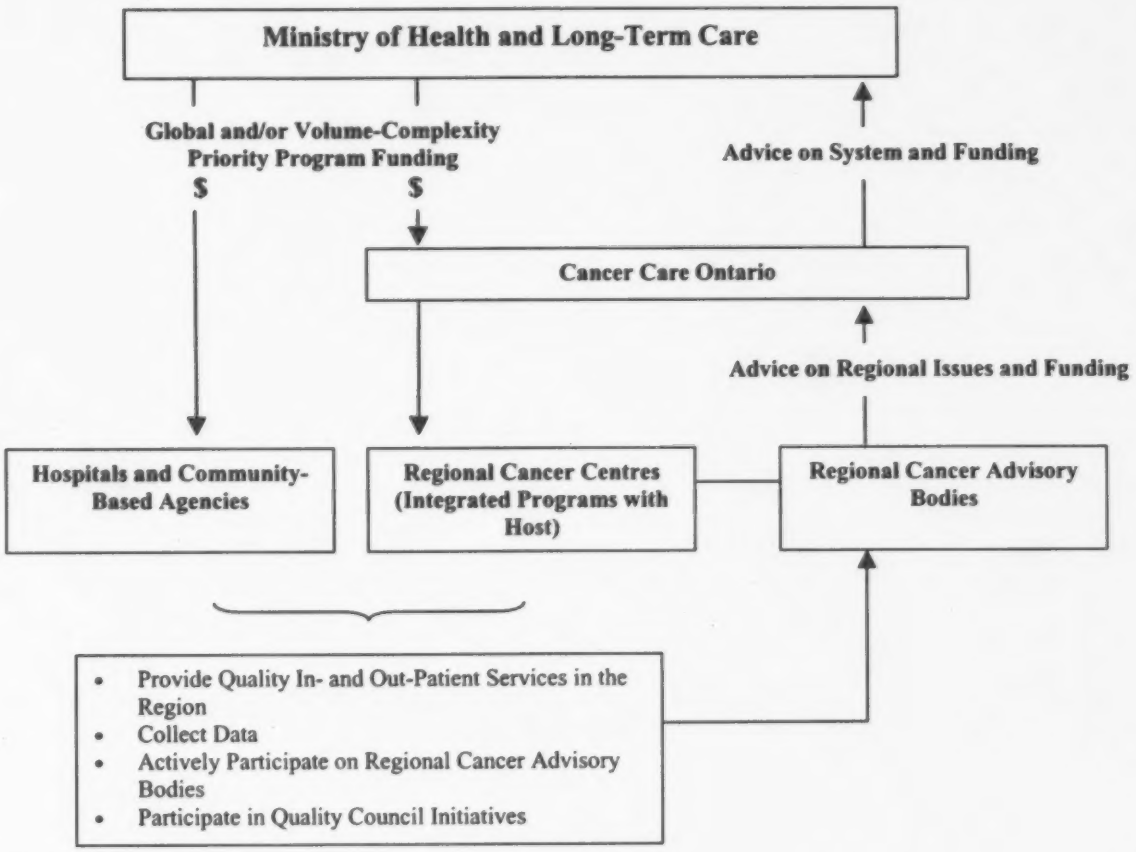
- Cancer care is fragmented and needs to be better co-ordinated;
- Information systems are fragmented and unable to support and monitor improvements in access, care and outcomes at the provincial, regional and local levels.
- A quality bar needs to be set and supported by standards to ensure that all patients receive the same quality care no matter where they live in the province;
- Funding approaches are inadequate to ensure appropriate cancer funding in hospitals;
- Although a complex array of cancer services is provided by many individuals, most of whom also care for non-cancer patients, a comprehensive picture of who these individuals are, what they do, how much they do and what their outcomes are, does not exist. The cancer services system is characterised by many governors and managers who only oversee pieces of the system.

The Committee concluded that fundamental shifts must occur at the advisory, governance and management levels for there to be improvements in the quality and integration of cancer care. Although the Committee determined the current structure of governance and management of cancer services should remain at this time, it recommended the following key changes (Figure 10).

- CCO's role as advisor on *all* cancer services should be strengthened. Its mandate will also be expanded to include developing standards and guidelines to support quality cancer care across the continuum, monitoring system performance, addressing problem areas, ensuring timely and equitable access to care, and ensuring the effective use of resources to support the full continuum of cancer services. In terms of its management responsibilities, CCO should delegate more operational authority to the regional centres for local decision making. As well, efforts should be made to integrate the activities of regional centres and host hospitals.

- Regional activities should be strengthened through the establishment of Regional Cancer Advisory Bodies. Made up of a broad range of stakeholders in the region, these bodies would facilitate discussion and decision-making among cancer providers so as to improve the quality and integration of cancer services in the regions. The key focus of activity to develop integrated care should be at the regional level. Indeed, the regional bodies will make up the Cancer Care Ontario System. The regional centres should support the regional bodies and actively facilitate the participation of other cancer service providers in the region.

Figure 10: Recommended Model – Funding and Advice


Ministry of Health and Long-Term Care
Global and/or Volume-Complexity Priority Program Funding
$
$
Advice on System and Funding
Cancer Care Ontario
Advice on Regional Issues and Funding
Hospitals and Community-Based Agencies
Regional Cancer Centres (Integrated Programs with Host)
Regional Cancer Advisory Bodies
• Provide Quality In- and Out-Patient Services in the Region
• Collect Data
• Actively Participate on Regional Cancer Advisory Bodies
• Participate in Quality Council Initiatives

The Ministry must have a consistent policy on cancer as a priority program that recognises the continuum of cancer services and the activities of other key providers. This should be supported with a number of key elements:

- A cancer information strategy that will be the backbone for an integrated cancer services system. The strategy should include management and clinical information,

an integrated patient record and a fully-linked comprehensive database to support research.

- A Cancer Quality Council to monitor, assess and improve clinical and health system performance of all cancer services in Ontario.
- A comprehensive and consistent funding approach for cancer services in the province that includes an envelope of funds that are protected for cancer and allocated using volume, complexity and quality considerations. The envelope will gradually encompass the whole continuum of cancer services in the province as part of an integrated approach.
- A provincial cancer human resources strategy to support the training, recruitment and retention of a sufficient number of professionals to provide cancer services.
- Strategies to support the professional development of, and advance communication between, providers. This will improve timely access to care and result in more co-ordinated patient care.

Additional recommendations on supporting research, and new technologies and pharmaceuticals will further enhance and strengthen the cancer services system.

To ensure that the recommendations are addressed, the Committee believes that the Ministry in partnership with CCO should:

- Seek comments from key stakeholders on the report with the goal of obtaining feedback and commitment to participate in the recommended initiatives;
- Develop an action plan that identifies key deliverables in relation to the recommendations and identifies responsibilities and deadlines for completion;
- Determine legislative changes that are required to fulfil the recommendations; and
- Conduct a costing analysis to determine the funding required to support the recommendations.

The Committee recommends that:

R23 The Ministry of Health and Long-Term Care, in partnership with Cancer Care Ontario and other stakeholders, work to develop and implement an action plan that will realise the fulfilment of the recommendations of this report. The plan should include key deliverables, clear priorities, responsibilities and timelines, as well as a determination of the legislative and funding requirements to support the recommendations.

The Committee believes that it has addressed the terms of reference as set out by the Minister: to improve integration of cancer services at a local level in the province, and to improve quality of patient care and productivity and efficiency in the cancer services components of the Ontario health system. In addition, the Committee believes that its recommendations are a key transition step that will facilitate the move to the full integration of cancer services in the province, and position the cancer services system to meet the challenges of the future.

SUMMARY OF RECOMMENDATIONS

GOVERNANCE, MANAGEMENT AND ADVISORY STRUCTURES TO SUPPORT INTEGRATION AND ACCOUNTABILITY

The Committee recommends that:

R1 The role of Cancer Care Ontario be strengthened as principal advisor to the Minister of Health and Long-Term Care on all matters related to the cancer control system and cancer control services. CCO must provide comprehensive and strategic advice to the Minister that is objective, and based on an analysis of needs and evidence, and involves the active participation of its stakeholders in building consensus. This advice should focus on the cancer services system and address current and future issues at the provincial, regional and local levels.

R2 The Ministry of Health and Long-Term Care designate the broad continuum of cancer services as a provincial priority program. This designation should be communicated to all facilities and professionals who provide cancer services in Ontario.

R3 Cancer Care Ontario focus on and be accountable for providing strategic direction for the cancer services system, developing standards and guidelines to support quality cancer care across the continuum, monitoring system performance, addressing problem areas, ensuring timely and equitable access to care, ensuring the effective use of resources to support the full continuum of cancer services, and publicly reporting on system performance.

R4 The Ministry of Health and Long-Term Care, in partnership with Cancer Care Ontario, review the current structure and selection process of the CCO board to ensure that these are appropriate for obtaining the strategic, executive and clinical expertise required on the board to support CCO's role, as recommended in this report.

R5 Regional Cancer Advisory Bodies be established by the board of Cancer Care Ontario to plan and oversee, on an ongoing basis, the integration of all regional cancer services. These bodies should be accountable to CCO for integrating and co-ordinating cancer services regionally, implementing standards and guidelines in the regions, overseeing the quality and performance of services, and providing advice to CCO on regional cancer funding. This information should be communicated to regional stakeholders. To help ensure the success of the Bodies they should: i) have adequate resources to support information technology and staff; ii) have a strong focus on obtaining regional input; iii) have responsibility for monitoring the implementation of standards and guidelines, and overseeing the quality of services and the performance of providers; iv) have broad-based, balanced representation of providers in the region; and v) include the active

participation of consumer representatives and a senior regional official from the Ministry of Health and Long-Term Care.

R6 The activities of the regional cancer centres be enhanced in two ways: i) CCO should delegate more operational authority to the regional cancer centres for local decision making; and ii) the regional cancer centres should support the regional cancer bodies and actively facilitate the participation of other cancer service providers in the region.

R7 As a transition step towards greater integration, all existing and new regional cancer centres move towards greater integration of cancer services into one program with host hospitals. This includes establishing a joint oncology program, having single leadership for the integrated oncology program, having joint support staff, and developing annual joint operating plans for the integrated program.

R8 The following be put in place to support the proposed governance and management model for cancer services: i) strong support from hospitals to provide cancer services as a priority program; ii) strong support from CCO for developing the regions; iii) development of a clear mandate, authorities, accountabilities and reporting requirements for the provincial, regional and local levels with Ministry support and stakeholder acceptance of these definitions; and iv) changes in legislation to ensure that CCO is clearly responsible for advising on standards and quality of all cancer services in the province. (This should include the provision for appointment of a supervisor in the event that CCO is not meeting its responsibilities as set out in legislation).

BEST PRACTICES AND QUALITY OUTCOMES

The Committee recommends that:

R9 A Cancer Quality Council be established within Cancer Care Ontario with the purpose of monitoring, assessing and improving the clinical and health system performance of all cancer services in Ontario. These services include health promotion and disease prevention, screening and early detection, primary care, diagnosis, treatment, rehabilitation, home/community care, palliative and supportive care.

R10 The Cancer Quality Council have four key responsibilities: i) Oversee the development of evidence-based guidelines, care pathways, standards and performance indicators using a systematic approach that includes an action plan with clear deliverables and timelines for the development of these tools; ii) Develop a strategy to support the successful implementation of these tools at the regional and local levels; iii) Develop and maintain a performance improvement process that includes monitoring, implementing and follow-up, targets quality performance improvements and the prevention of medical and system-errors, and

identifies problem areas before they become crises; and iv) Ensure that the results of performance assessments are evaluated and compiled centrally either by an external expert body or by such a body in partnership with Cancer Care Ontario. The results should be communicated to the public and providers through annual accountability reports and other methods.

FUNDING

The Committee recommends that:

R11 The Ministry of Health and Long-Term Care, on the advice of Cancer Care Ontario and others, develop a comprehensive and consistent funding approach for cancer services in the province that includes: i) an envelope of funds that are protected for cancer services; and ii) an allocation methodology that incorporates volume, complexity and quality factors.

R12 The Ministry of Health and Long-Term Care develop processes to monitor accountability for the funds allocated for cancer-related services at the local, regional and provincial levels.

R13 The Ministry of Health and Long-Term Care develop alternate funding mechanisms for physicians who provide cancer services.

INFORMATION

The Committee recommends that:

R14 The Ministry of Health and Long-Term Care fund and work with Cancer Care Ontario and other stakeholders to implement a cancer information strategy that includes the systematic development of a provincial management information system, a clinical information system, a regionally-integrated electronic record at the local level, and a fully-linked comprehensive data set that can be used to support research. The strategy should establish priorities within available resources, incorporate manageable steps that gradually build a comprehensive system, involve key stakeholders, capitalise on available expertise, use effective and efficient means to achieve goals, and seek efficiencies through joint ventures and contracting arrangements.

R15 The Union Internationale Contre le Cancer staging system be used consistently to stage all cancer patients in the province. In disease sites where the UICC stage is inappropriate or unavailable, experts from these disease sites should use a consensus approach to determine an acceptable disease staging system for implementation across Ontario.

R16 A process and system be developed for uniform pathology reporting in Ontario.

HUMAN RESOURCES

The Committee recommends that:

R17 Cancer Care Ontario continue to develop a provincial cancer human resource strategy to support the training, recruitment and retention of a sufficient number of appropriately trained professionals to provide the full range of cancer services. This strategy should complement the Ministry's overall provincial human resource strategy for health, and include regional and local approaches and initiatives to improve the recruitment and retention of these providers. In addition, the Ministry should ensure that there are an appropriate number of funded training spaces to support an adequate supply of the full range of cancer service providers required for the future.

PATIENT- AND PROVIDER-FOCUSED EDUCATION AND COMMUNICATION

The Committee recommends that:

R18 Cancer Care Ontario, in partnership with other stakeholders, develop initiatives to support the professional development of providers using team and mentoring approaches to care.

R19 Cancer Care Ontario, in partnership with other stakeholders, develop a strategy that supports continuous communications between *all* providers of cancer services in the province and their patients.

RESEARCH

The Committee recommends that:

R20 The Ministry of Health and Long-Term Care continue to provide resources to support an innovative program of research that maximises the development of evidence for best practices, improves approaches to patient care and fosters clinical trials. Research initiatives should be supported with innovative strategies such as funding incentives for clinical trials. The Ministry should also challenge both the provincial and federal levels of government to expand research funding.

NEW TECHNOLOGIES AND PHARMACEUTICALS

The Committee recommends that:

R21 The Ministry of Health and Long-Term Care continue to maintain the New Drug Funding Program through Cancer Care Ontario, and monitor the ongoing impact of this initiative. CCO should also maintain, expand and continuously update its Drug Formulary.

R22 Cancer Care Ontario, in partnership with other stakeholders, participate in ongoing evaluations of new and existing technologies, and anti-cancer and supportive drugs. Based on the results of these evaluations, CCO should advise the Ministry of Health and Long-Term Care on whether to fund and/or purchase these drugs and technologies, and where they should be offered and/or sited.

CONCLUSION

The Committee recommends that:

R23 The Ministry of Health and Long-Term Care, in partnership with Cancer Care Ontario and other stakeholders, work to develop and implement an action plan that will realise the fulfilment of the recommendations of this report. The plan should include key deliverables, clear priorities, responsibilities and timelines, as well as a determination of the legislative and funding requirements to support the recommendations.

APPENDICES

APPENDIX A: APPOINTMENT OF CHAIR OF THE CANCER SERVICES IMPLEMENTATION COMMITTEE

June 5, 2001

Dr. Alan Hudson
Toronto Ontario

Dear Dr. Hudson:

I am pleased to welcome you as Chair of the Cancer Services Implementation Committee. I believe the work of this committee will benefit from the depth of knowledge and richness of experience that you are bringing to this important work. I look forward to receiving your report and recommendations at the conclusion of your committee's work.

Thank you.

Yours very truly,

Tony Clement
Minister of Health and Long-Term Care

APPENDIX B: TERMS OF REFERENCE FOR THE CANCER SERVICES IMPLEMENTATION COMMITTEE

Purpose

On June the 5th 2001, the Minister appointed Dr. Alan R. Hudson as Chair of the Cancer Services Implementation Committee. This independent committee will deliver a report to the Minister of Health and Long-Term Care in six months time.

Goal

The essential goal is that of making recommendations to improve integration of cancer services at the local level in the Province of Ontario. These recommendations should result in the improved quality of patient care and improved productivity and efficiency in the cancer service component of the Ontario Health System.

The committee should examine the current situation and suggest modifications or alternative models. It is anticipated that the committee will develop principles in support of integration of cancer service at the local/regional level. The site of governance and management authority, responsibility and accountability should be clearly demarcated in the model(s) recommended by the committee.

Methodology

This independent committee should set its own agenda and work plan. The committee should consult with stakeholders and receive input from the public. The ministry will provide support services to the committee.

APPENDIX C: COMMITTEE MEMBERS AND SUPPORT STAFF

Alan Hudson, MB
Chair, Cancer Services Implementation Committee

Arnie Aberman, MD
Professor of Medicine, University of Toronto
(Previously Dean, Faculty of Medicine, University of Toronto)

Robert Bell, MD
Cancer Surgeon and Chief Operating Officer, Princess Margaret Hospital

Don Cowan, MD
Cancer Physician and Senior Consultant to Cancer Care Ontario

John Evans, MD
Chair Torstar Corporation
(Previously President, University of Toronto)

Martin Girash, PhD
President and CEO, Windsor Regional Hospital

Peter Glynn, PhD
Health Care Consultant
(Previously President and CEO, Kingston General Hospital

Raylene Godel, RN
Trustee, Board of Cancer Care Ontario

Vickie Kaminski
President and CEO, Sudbury Regional Hospital

John Kime
President and CEO, London Economic Development Council
Chair, Cancer Care Ontario Regional (Southwest) and Trustee, CCO Board

Andreas Laupacis, MD
CEO, Institute for Clinical Evaluative Sciences

Peggy Leatt, PhD
Liberty Health Chair – Health Management Strategies, University of Toronto
(Previously CEO, Health Services Restructuring Commission)

Donald Lenz,
Managing Director, Brompton Securities Ltd.
Trustee, Board of Cancer Care Ontario

Les Levin, MD
Senior Medical Advisor and Head of the Medical Advisory Secretariat
Ministry of Health and Long-Term Care

Margaret Mottershead
President and CEO, Mottershead Consultants
(Previously Deputy Minister, Ontario Ministry of Health and Long-Term Care)

Karen Pappin, PhD
President and CEO, Karen Pappin and Associates

Carol Sawka, MD
Cancer Physician and CEO, Toronto Sunnybrook Regional Cancer Centre

Hartley Stern, MD
Cancer Surgeon and CEO, Ottawa Regional Cancer Centre

Anthony Whitton, MD
Cancer Physician, Hamilton Regional Cancer Centre and Provincial Coordinator,
Radiation Treatment Program, CCO
(Previously Head of Radiation Oncology, Hamilton Regional Cancer Centre)

Consultant to the Committee

Joann Trypuc, PhD

Ministry of Health and Long-Term Care Staff

Elaine Bishop
Program Consultant, Hospitals Branch

Carole McKeogh, LLM
Legal Counsel

Sandy Nuttall, PhD
Program Consultant, Hospitals Branch

Shannon Tyler
Communications Officer, Hospitals Branch

APPENDIX D: PRESENTATIONS, CONSULTATIONS AND LITERATURE REVIEW

1. PRESENTATIONS TO THE COMMITTEE

Presentations Made by Invited Guests

July 19, 2001
- Wayne Fyffe and Dr. Sheldon Fine, *The Credit Valley Model*

July 26, 2001
- Murray Martin, *The Hamilton Health Sciences Centre Model*

September 6, 2001
- Dr. Brian Dingle, *Grand River Regional Cancer Centre Model*
- Paula Freedman and Micheline Mistruzzi (Canadian Institute for Health Information), *Information Technology Data*
- Dr. Michael Guerriere (HealthLink), *Information Requirements*
- Mark Vimr (with Vickie Kaminski), *Cardiac Care Network*

September 20, 2001
- Dr. Bob Phillips, *Ontario Cancer Research Network*
- Graham Scott, *Cancer Care Ontario*
- Ted Wheatley (with Penny Thomsen), *Canadian Cancer Society – Ontario Division*

October 25, 2001
- Tom Closson, *Experience as a CEO of Sunnybrook, Princess Margaret Hospital and in Victoria, BC*

November 15, 2001
- Ted Johnson, *The CCOR Experience in Eastern Ontario*
- Graham Scott, *Cancer Care Ontario Board-Approved Position*

Presentations Made by Committee Members and Staff

July 12, 2001
- Dr. Andreas Laupacis, *Data Sources*
- Carole McKeogh, *Overview of the Cancer Act, Public Hospitals Act and The Toronto Hospitals Act*
- Margaret Mottershead, *Funding*

July 19, 2001
- Dr. Don Cowan, *Cancer Care Ontario Overview*
- Dr. Carol Sawka, *The Sunnybrook Model*

July 26, 2001
- Dr. Bob Bell, *The Princess Margaret Hospital Model*
- Dr. Peter Glynn, *Current State of Cancer Services in Ontario*
- Dr. Peggy Leatt, *Principles of Governance and Management*

September 20, 2001
- Dr. Les Levin, *Provincial Cancer Network, Before and After*

October 11, 2001
- Dr. Joann Trypuc, *Cancer Models in Other Jurisdictions: British Columbia, Alberta, Quebec and the United Kingdom*

November 1, 2001
- Dr. Joann Trypuc, *Models of Integration – The Cardiac Care Network and the Coordinated Stroke Strategy*
- Dr. Joann Trypuc, *Cancer Models in Other Jurisdictions: Australia and New Zealand*

November 15, 2001
- Dr. Hartley Stern, *Key Components for an Integrated System for Cancer Surgery*

2. CONSULTATIONS

Site Visits to the Regional Cancer Centres

- Durham (Oshawa) Regional Cancer Centre Under Development (Alan Hudson, Chair)
- Grand River (Kitchener) Regional Cancer Centre Under Development (Alan Hudson, Chair)
- Hamilton Regional Cancer Centre (Alan Hudson, Chair)
- Kingston Regional Cancer Centre (Alan Hudson, Chair)
- London Regional Cancer Centre (Alan Hudson, Chair)
- Northeastern Ontario (Sudbury) Regional Cancer Centre (Alan Hudson, Chair)
- Northwestern Ontario (Thunder Bay) Regional Cancer Centre (Alan Hudson, Chair)
- Northwestern Ontario (Thunder Bay) Regional Cancer Centre (Shannon Tyler, Ministry of Health and Long-Term Care)
- Ottawa Regional Cancer Centre (Alan Hudson, Chair)
- Port Credit Regional Cancer Centre Under Development (Alan Hudson, Chair)
- Toronto-Sunnybrook Regional Cancer Centre (Alan Hudson, Chair)
- Windsor Regional Cancer Centre (Alan Hudson, Chair)

Consultations (Public and Invitational)

August 30, 2001 – Toronto
Ms. Cheryl Batty, Waterloo Region - Wellington - Dufferin District Health Council
Ms. Wendy Bell, Private Citizen

Ms. Valerie Hepburn, Canadian Breast Cancer Foundation
Ms. Beth Kapusta, Cancer Advocacy Coalition of Canada
Ms. Pat Kelly, Cancer Advocacy Coalition of Canada
Dr. Larry Librach, Ontario Palliative Care Association
Dr. J.D. May, Cambridge Memorial Hospital
R. Miller & B. Morrison, Hoffmann - La Roche Limited
Ms. Elisabeth Ross, National Ovarian Cancer Association
Mr. Jack Shapiro, Toronto Cancer Prevention Coalition
Dr. Henry Solow, COMET
Mr. Joe Witalis, Cancer Advocacy Coalition of Canada
Dr. Vincent Young, The Medical Oncology Associates of Cancer Care Ontario
(Dr. Alan Hudson, Committee Chair)

October 24, 2001 – Kingston
(Dr. Alan Hudson, Committee Chair)

October 31, 2001 – Sudbury
Mr. Randy Bisset, Northeastern Ontario Regional Cancer Centre
Dr. Bowen, Oncologist Northeastern Ontario Regional Cancer Centre
Mr. Cyril Fry, Cancer Survivor
Ms. Connie Innis, Canadian Cancer Society
Ms. Maureen Lacroix, Community Members
Mr. Gerry Lougheed Jr., Community Members
Mr. Manu Malkani, President and CEO, Sault Area Hospitals
Ms. Janet Skot, Northeastern Ontario Regional Cancer Centre
Mr. Esko Vanio, President and CEO, Timmins and District Hospital
(Ms. Vickie Kaminski and Dr. Karen Pappin, Committee Members)

November 13, 2001 – Thunder Bay
(Dr. Karen Pappin, Committee Member)

Consultations With Health Care Organisations, Associations and Groups

June 25, 2001
Systemic Therapy Task Force, Ministry of Health and Long-Term Care

September 13, 2001
Ontario Nurses' Association

September 21, 2001
Ontario Medical Association

October 3, 2001
Service Employees International Union (SEIU) Local 204

October 4, 2001
Service Employees International Union (SEIU) National

October 11, 2001
Canadian Union of Public Employees (CUPE)

October 17, 2001
Ontario Hospital Association

October 18, 2001
Ontario Public Service Employees Union (OPSEU)
Profession Institute of the Public Service of Canada (PIPSC)

November 8, 2001
The Ontario College of Family Physicians

December 17, 2001
Ontario Medical Association Section on Laboratory Medicine

3. LITERATURE REVIEW

Cancer Care Ontario. "Building a cancer care workforce" *Cancer Care* Vol. 5 (2), Summer 2001.

Ben Chan and Wendy Young, "Burden of Cardiac Disease" In C. David Naylor and Pamela M. Slaughter (eds.) *Cardiac Health & Services in Ontario: An ICES Atlas*. Toronto: Institute for Clinical Evaluative Sciences, 1999. Pp. 1-13.

Heart and Stroke Foundation of Canada, *Annual Report Card on Canadians' Health*, February 2001.

Heart and Stroke Foundation of Ontario, *Stroke Rehabilitation Consensus Panel Report: Submitted to the Heart and Stroke Foundation of Ontario*, May 2000.

Heart and Stroke Foundation of Ontario and the Ontario Ministry of Health and Long-Term Care, *Towards an Integrated Stroke Strategy for Ontario: Report of the Joint Stroke Strategy Working Group*, June 2000.

Thomas H. Hostetter "Editorial" *New England Journal of Medicine*, Vol.345 (12), September 20, 2001. Pp. 910-912

Memorandum of Understanding made the eighth day of November, 1999 between the Ministry of Health and Long-Term Care (Ontario) and Cancer Care Ontario.

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APPENDIX E: ADDITIONAL DETAIL ON CANCER MODELS IN ONTARIO

1. CANCER CARE ONTARIO

Cancer Care Ontario (CCO) was created in April 1997. It is an operational service agency of the Ministry of Health and Long-Term Care, is governed by the *Cancer Act,* and operates within the context of a Memorandum of Understanding with the Ministry (November 8, 1999). CCO has its roots in the Ontario Cancer Treatment and Research Foundation (OCTRF) which was established by the *Ontario Cancer Treatment and Research Foundation Act* of 1943. OCTRF was mandated to take responsibility for the treatment, research and diagnosis of cancer. The Foundation controlled the delivery of radiation therapy in designated cancer centres. As medical oncology evolved, OCTRF assumed an active role in the provision of systemic therapy as well as radiation provided by designated centres.

In 1995, the government announced that the mandate of OCTRF was to evolve. A new mandate and name change to Cancer Care Ontario was finalised in May 1997. The new mandate expanded the organisation's role to include the full spectrum of cancer control by adding prevention and supportive care.

The vision of CCO is to lessen the burden of cancer in Ontario by ensuring that all residents have timely, equitable access to an integrated system of excellent coordinated and efficient programs in prevention, early detection, treatment, education and research.

Board

Cancer Care Ontario (CCO) has a provincial board with 25 members appointed by Order in Council.

CCO operates eight regional cancer centres. Each of these centres has a Cancer Care Ontario Regional Council (CCOR). Each CCOR is comprised of Board-approved regional stakeholders. The chair of each CCOR sits on the CCO board. Both CCORs and regional centres are ultimately accountable to the CCO board.

Administrative Structure and Activities

CCO has a provincial office in Toronto that supports the eight regional cancer centres.[35] A centre in Kitchener (Grand River) is scheduled to open in 2002. Four additional centres are in various stages of planning – Peel, Durham, Niagara and Algoma. The regional centres provide radiation and systemic therapy services. CCO centrally

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[35] The current regional cancer centres are Toronto-Sunnybrook Regional Cancer Centre (RCC), Hamilton RCC, London RCC, Windsor RCC, Northeastern Ontario RCC (Sudbury), Northwestern Ontario RCC (Thunder Bay), Kingston RCC, Ottawa RCC. The three centres scheduled to open are in Kitchener (Grand River), Peel (Credit Valley) and Durham (Lakeridge).

coordinates, funds, and is the employer of staff at these centres. Each regional centre has a CEO – a physician – who manages the resources locally.

To integrate and coordinate services, CCO operates eight regional councils (CCORs) located across the province. The Memorandum of Understanding between the Ministry and CCO defines CCORs as "regional committees of CCO, established under CCO by-law which are responsible for the co-ordination of cancer control services, the promotion of standards and guidelines on a regional basis and the promotion of appropriate access of patients to cancer facilities. This co-ordination and promotion is carried out through affiliation agreements with other organisations and through regional provider networks in the areas of treatment, supportive care, prevention, research and education so that cancer control services are complementary, consistent and predictable in every region."

The Cancer Transition Team report recommended in 1996 that CCOR Councils be representative-based, with an optimal size of 20 members reflecting a geographic balance and be representative of providers, provider organisations and community representatives.[36] Each CCOR has affiliation agreements with major stakeholders including hospitals, community care access centres and the Canadian Cancer Society.

CCO operates a number of provider networks that have been established regionally in service areas such as supportive care and surgical oncology, and provincially (e.g., Ontario Cancer Genetics Network, Ontario Network for Cancer Prevention). CCO also operates the Ontario Breast Screening Program, the Ontario Cervical Screening Program, the New Drug Funding Program and the Ontario Cancer Registry.

The administrative functions of the provincial office include:

- Key contact for regional cancer centres with the Ministry;
- Strategic, operating and business planning functions;
- Board secretariat and support;
- Budget and audit control over regional cancer centres and provincial programs;
- Human resource policy development and labour relations for all CCO staff, working with regional centre human resources personnel;
- Administer the provincial training program for radiation physicists, as well as a Provincial professional recruitment program;
- Set standards and guidelines for professional practice and treatment;
- Surveillance of cancer incidence and mortality rates through the provincial cancer registry, and track radiation and systemic therapy utilisation in CCO cancer centres;
- Operate organised screening programs including the Ontario Breast Screening Program and the Ontario Cervical Screening Program;
- Manage the New Drug Funding Program (which also provides new expensive systemic therapy drugs to hospitals) and its guidelines;

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[36] *Report of the Cancer Transition Team: Recommendations for Creating Cancer Care Ontario.* Submitted to the Deputy Minister of Health, January 6, 1997.

- Operate province-wide networks such as the Ontario Cancer Genetics Network and the Ontario Network for Cancer Prevention;
- Allocate reserve funds for research purposes and oversee the CCO research program executed regionally;
- Facilities planning including the establishment of the new regional cancer centres; and
- Provide expertise in purchasing and commissioning radiation machines.

The administrative functions of the regional cancer centres include:

- Employment of regional staff;
- Ownership and control of all equipment and furnishings inside regional cancer centres, although the building and land is owned by the hospital;
- Budget preparation and submission to the Provincial office.;
- Deliver ambulatory radiation and systemic therapy services;
- Provide multidisciplinary consultation and treatment planning;
- Human resource, facilities and financial management;
- Research programs - clinical and laboratory-based;
- Regional repository of cancer expertise and regional focus for provincial treatment guideline initiative;
- Co-ordinate regional delivery of systemic therapy with community-based hospitals; and
- Infrastructure support to CCORs and leadership to CCOR professional regional networks.

Research

CCO supports a number of research programs including:

- The Research Unit in the Division of Preventive Oncology which focuses on cancer prevention and cancer screening research;
- The Ontario Clinical Oncology Group which conducts clinical trials on the effectiveness of cancer treatment regimens;
- The Radiation Oncology Research Unit which pursues research to improve decisions about the use of radiotherapy in the management of cancer;
- The Supportive Care Cancer Research Unit whose work is used to enhance the identification of supportive care needs of cancer patients and facilitate the development, evaluation, and coordination of supportive care services to help meet those needs;
- The Ontario Cancer Genetics Network which conducts studies to improve the care of patients with hereditary ovarian, breast or colon cancer;
- The Program in Evidence-Based Care which develops practice guidelines; and
- Block funding for basic and translational research at each of the regional cancer centres.

Funding

CCO has a provincial office in Toronto that supports the eight regional centres. In 2000/01, CCO had revenues of $284.4 million of which $244 came from the Ministry. CCO employs approximately 2,300 staff most of whom work in the regional centres. CCO's budget for radiation services is $60 million per year, $30 million per year for systemic therapy services and $37 million for the provincial new cancer drug program.

Since 1999, CCO has been funded to provide an intra-provincial and out-of-country re-referral program for breast and prostate cancer patients. Between the launch of this program in March 1999 and December 1, 2000, 2,035 breast and prostate cancer patients have been re-referred, with 1,539 sent to the United States for radiation treatment. The remaining 496 patients have been sent from their local regional cancer radiation centre to Ottawa, Kingston, Northeastern Ontario (Sudbury) and Northwestern Ontario (Thunder Bay).

Clinical Activities

Through the eight regional centres, CCO provides 75% of all radiation treatments in the province and 50% of all systemic treatments.

Regional Cancer Centre-Host Hospital Linkages

A few regional centres and host hospitals have joint venture agreements which reflect a comprehensive array of in- and out-patient cancer treatments. The majority of regional centres and host hospitals, however, operate relatively independently of each other. Agreements vary depending on local circumstances. Four examples are provided for illustration purposes: the Toronto-Sunnybrook Regional Cancer Centre, the Hamilton Regional Cancer Centre and the Grand River Regional Cancer Centre.

1a. The Toronto-Sunnybrook Regional Cancer Centre

The Toronto-Sunnybrook Regional Cancer Centre (T-SRCC) is a partnership between CCO and Sunnybrook and Women's College Health Sciences Centre as a host hospital. This regional comprehensive cancer centre brings together, as a single entity, the ambulatory programs in the regional cancer centre and the in-patient cancer program of the host hospital. T-SRCC operates patient care, teaching, and research programs that span the range of cancer control including prevention, screening, diagnosis, treatment, supportive care and palliation.

The CEO of T-SRCC is accountable to the Presidents and CEOs of CCO and the host hospital and ultimately to the Boards of each organisation. The CEO is accountable to each Board for the appropriate use of its respective resources.

There is a single leadership structure for the ambulatory and in-patient aspects of cancer care at T-SRCC. The CEO of the T-SRCC is the Medical Vice-President, Oncology at

the host hospital, and has overall medical and budgetary responsibility for the activity and resources of the in-patient oncology activity, including the patient service units of the host hospital. This hospital activity includes patient care units for medical, radiation and surgical oncology and increasing responsibility for operating room allocation and critical care resources for cancer surgery.

The CEO of the T-SRCC is a member of the host hospital's senior management team, the CEO's Strategy Council and the Medical Advisory Committee. The hospital's Cancer Program's administrative director is also responsible for T-SRCC's ambulatory clinical programs. The heads of the T-SRCC systemic and radiation treatment programs are division/department heads and report to the departments and Medical Advisory Committee on academic and quality of care matters.

The T-SRCC Advisory Board consists of members of the boards and senior management committees of CCO and the hospital. The T-SRCC Advisory Board is the vehicle to advise the CEO of T-SRCC on strategic budget and management issues, to ensure that the T-SRCC strategic plan aligns with the strategic plans of CCO and the hospital, and to advocate on issues such as access to imaging, operating rooms and health promotion.

CCO and the hospital flow funds to a single administrative structure (T-SRCC). These funds are used in the cancer program at the discretion of the CEO. CCO flows funds for all radiation and ambulatory systemic treatment delivered at T-SRCC, base salary support for medical oncologists, radiation oncologists, nursing and clerical staff in T-SRCC, and the administration and management of T-SRCC.

The hospital flows funds for patient service units for radiation, and surgical and medical oncology requirements, supportive care staff, inpatient facility costs, diagnostic imaging and laboratory services for the entire ambulatory and inpatient oncology program (these services are not part of the direct oncology inpatient budget at this time, but are provided separately).

CCO and the hospital share funding for surgical oncology, preventive oncology, advanced therapeutics, research, education and some administrative costs.

CCO employs all staff in radiation treatment program including dosimetrists, therapists and physicists, all medical and radiation oncologists, nursing and clerical staff in the ambulatory clinics at T-SRCC, and management staff (some may be joint appointments with the hospital). The hospital employs all inpatient staff, pharmacy staff, diagnostic services staff, and staff in some administrative roles. In addition, some staff may be shared between the two organizations

1b. The Hamilton Regional Cancer Centre

Over the past year, the Hamilton Regional Cancer Centre (HRCC) and the Henderson site of the Hamilton Health Sciences Centre have integrated their operations more closely. Given separate governance and funding structures, the organisations agreed to develop a

shared management arrangement that would include all in- and out-patient cancer services at the Henderson site. The model is under consideration by CCO.

The key features of the model are:

- The whole range of cancer services is in one program and one management structure.
- There is joint accountability to the host hospital and CCO.
- There is delegated management and authority with future plans for joint hiring and service delivery, and creating a department of oncology within the hospital. (Currently collective agreements and employment policies are separate for each organization.)
- HRCC will manage funds as one program envelope.
- Diagnostic services are under hospital management.
- The CEO of the HRCC is responsible to the hospital CEO for the operation of the hospital oncology program, and is a member of the senior management team and Medical Advisory Committee of the hospital.
- A regional steering committee will include the host hospital, HRCC, St. Joseph's Health Care Centre, and McMaster University.

1c. The Grand River Regional Cancer Centre

Grand River Regional Cancer Centre (GRRCC) created its affiliation agreement and operating model based on the T-SRCC model, and much of what is said above about T-SRCC applies to GRRCC. What follows are highlights of subtle differences, more apparent in the application than in the model.

GRRCC is still in its infancy regarding several programs specifically prevention, screening, teaching, research and surgical oncology. Not all senior management personnel are in place (e.g. Medical Director, Systemic Therapy arrives in the new year). The building itself is 60% complete.

The CEO of GRRCC is accountable to the Presidents and CEOs of both Grand River Hospital (GRH) and CCO, and ultimately to the boards of both organizations. There is a single leadership structure for ambulatory and in-patient oncologic care, and there is a commitment from this team to help provide solutions to oncologic care in the surrounding communities within the catchment area of the centre. Because it straddles two CCORs, currently GRRCC is represented on both CCOR-CW and -SW.

The CEO of GRRCC is a member of the host hospital's senior management team and core strategy group, at the level of Vice-President, and the hospital's joint Medical Advisory Committee (which is in partnership with St. Mary's General Hospital in Kitchener). Issues discussed are not exclusively oncologic, but include all aspects of the hospital operations and capital development. Physicians are part of the Department of Internal Medicine, Division of Oncology at both St. Mary's and Grand River Hospital.

The GRRCC Advisory Board has a similar structure to T-SRCC, though does not have a Board Member from either organization. Its function is the same.

Funds flow to the GRRCC from the Ministry through CCO and through GRH. Basically, CCO funds support ambulatory functions of the program, while hospital funds support the in-patient and laboratory/medical imaging functions. In general, the funding is protected for the oncology program under the auspices of the GRRCC, with surplus and deficit issues being the responsibility of the organisation from which the funding flows. In spite of this division of funding flow, the majority of the staff are employed by the hospital. CCO employs all physicians for their base salary, and all members of the Radiation Therapy Program (physicians, physicists, physics technologists, radiation therapists), while all nursing staff, allied health care support, clerical staff, finance, management (with the exception of the CEO) are employed by the hospital. Budgets and plans are submitted to both organizations for their respective responsibilities, and rolled into that organization's budgets and plans for submission to the Ministry. The GRRCC's budget and plan provide a picture of the entire oncology program.

Physically, the cancer centre is being built as part of the hospital, attached to the 'B' wing, with the oncology inpatient wing in close proximity to the doctors' offices and the outpatient units. Externally and internally, it will appear as one building. Many nursing staff and all other clinical staff work in both the in- and out-patient units. As a result, cross-coverage and continuity of care is relatively easy to maintain.

Supportive care is a critical part of the GRRCC, being the matrix within which all other care occurs. Palliative care is provided by independent practitioners but discussions are ongoing to find a way to integrate them into the program.

1d. The Peel Regional Cancer Centre

Credit Valley Hospital in Mississauga has proposed a Joint Venture Agreement with the vision of a fully integrated model of in- and out-patient care in partnership with the surrounding hospitals. This includes fully integrated information technology, enterprise-wide electronic record, linkages with referring hospitals including Sunnybrook and Women's College Health Sciences Centre and Princess Margaret Hospital, clinical pathways for all clinicians and comprehensive cancer care with community partners. The vision for a "virtual cancer program" also includes single governance and administrative structures, one system for human resources and finance, and a separate CCOR for Peel Region.

2. THE PRINCESS MARGARET HOSPITAL/UNIVERSITY HEALTH NETWORK

The cancer program at the University Health Network (UHN) is centred at the Princess Margaret Hospital. PMH is part of a network of hospitals – known as UHN – that also includes The Toronto General and Toronto Western hospitals. The vision of UHN is "to

be an internationally recognised academic health care system." One of the largest cancer hospitals in the world, PMH is recognised as having a unique role in the Ontario cancer system. It is a major world centre devoted exclusively to cancer care, research and teaching.

The key features of the PMH model are:

- Cancer surgery is performed at all three UHN hospitals but radiation and systemic therapy is exclusively offered at PMH.
- UHN has a single board, budget, CEO and information system. A standing committee of the board advises the board on all cancer matters. A cancer-specific community advisory committee advises the board committee. In addition, the Medical Advisory Committee has a cancer sub-committee.
- PMH has a Chief Operating Officer who reports to the CEO of UHN.
- The PMH concept is that the patient is surrounded by the complete range of cancer services (screening, prevention, diagnostics, systemic therapy, radiation, surgery, supportive and palliative care). Integrated care and integrated information systems are the core components of this model.
- When PMH and The Toronto Hospital merged to become UHN, the cancer budget was estimated to be $120 million. It was agreed that this proportion of the overall UHN budget for cancer would never decrease. As a result, UHN protects this proportion of its budget exclusively for cancer services. These funds cannot be used to support other UHN activities.

APPENDIX F: OBJECTIVES AND MANDATE OF CANCER CARE ONTARIO [37]

1. To reduce the burden of cancer on the people of Ontario;
2. To be the principal advisor to the Minister on all matters relating to the Cancer Control System and Cancer Control Services;
3. To be accountable for assessing, monitoring and reporting to the Minister on the organisation and status of the Cancer Control System and Cancer Control Services, including all matters relating to access, effectiveness and quality;
4. In co-operation with publicly funded providers and agencies and other key stakeholders to lead in the development of an overall strategic plan for the Cancer Control System and the delivery of Cancer Control Services in Ontario;
5. In co-operation with publicly funded providers and agencies and other key stakeholders to develop plans for presentation to the Ministry on resource distribution and coordination of all Cancer Control Services in the province as a whole and in each region of the province;
6. To develop through the [Cancer Care Ontario Regional Committees], in consultation with the [District Health Councils], regional plans for the delivery of Cancer Control Services in each region of the province and to recommend the plans to the Minister;
7. To plan, fund, provide and manage services in the Regional Cancer Centres, in partnership with hospitals and in other facilities as necessary;
8. To develop, disseminate, monitor, report on and encourage adherence to standards and guidelines for all Cancer Control Services;
9. To promote and contribute to the development and funding of cancer research, alone and in combination with other research funders;
10. In partnership with the Ministry, institutions of learning and other relevant parties, to plan, promote and contribute to the education and training of health professionals providing Cancer Control Services;
11. To promote and support programs designed to prevent cancer and programs in cancer related patient and public education;
12. To gather and disseminate information about cancer;
13. As necessary to further its objects and mandate, and in accordance with the provisions of this MOU and other agreements, the Freedom of Information and Protection of Privacy Act (FIPPA), the Act and other legislation, to directly or indirectly collect personal health information; and
14. To do any other things that it or the Minister considers necessary or advisable to attain its objects or fulfil its mandate.

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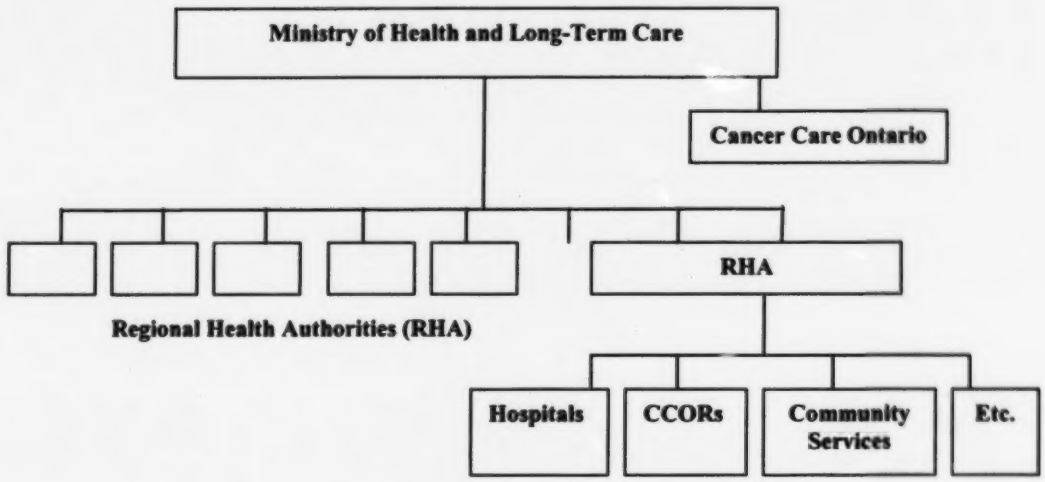
[37] *Memorandum of Understanding* made the eighth day of November, 1999 between the Ministry of Health and Long-Term Care (Ontario) and Cancer Care Ontario.

APPENDIX G: MODEL OPTIONS

Option 1: Regional Health Authorities



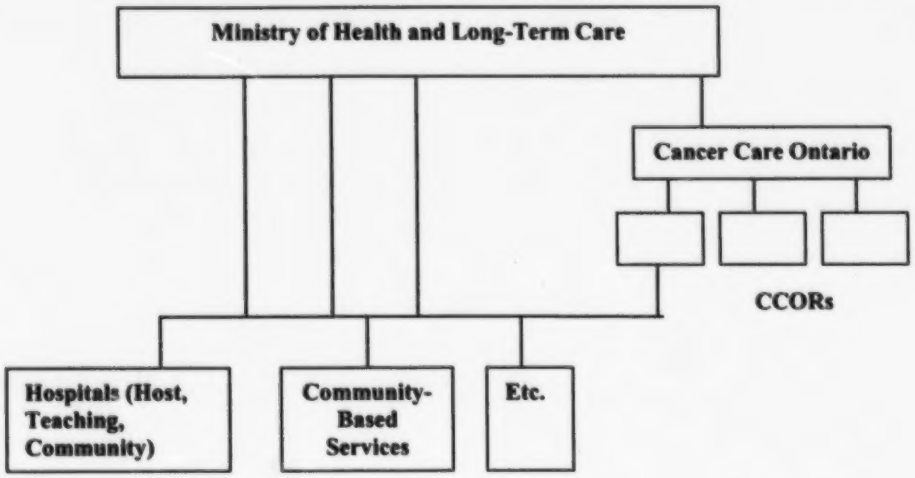
Key Features

- Establish a system of regional health authorities.
- Give each region a funding envelope to pay for all health services in the region.
- The regional authority determines the governance and management of cancer care.

Summary of Committee Observations

- This option would ensure that cancer services address local needs.
- The challenge is that cancer would be set up as a separate "silo" since Ontario does not have regional health authorities. The lack of a recognised regional system makes the success of this option unlikely at the present time.

Option 2: Expand the Role of CCO



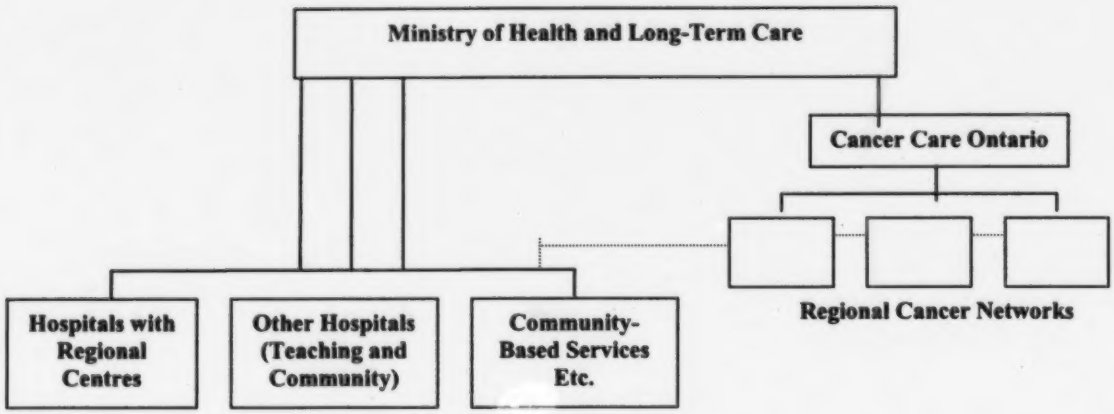
Key Features

- Expand CCO's role by giving it governance and management authority for all in- and out-patient cancer care, and responsibility for linking with host and community hospitals, community-based providers, and community advisors in each region.

Summary of Committee Observations

- This option would establish one body with clear delegated authority for governing and managing the system in a consistent fashion.
- The challenge is that it would eliminate local governance authority and accountability to the community for cancer services, probably lead to a decrease in local community support, and result in cancer services that are not integrated with other hospital services. The fact that CCO would need to expand its authority over 80% of the cancer system that it does not currently govern/manage, makes the success of this option unlikely.

Option 3: Expand the Role of Hospitals


Ministry of Health and Long-Term Care
Cancer Care Ontario
Regional Cancer Networks
Hospitals with Regional Centres
Other Hospitals (Teaching and Community)
Community-Based Services Etc.

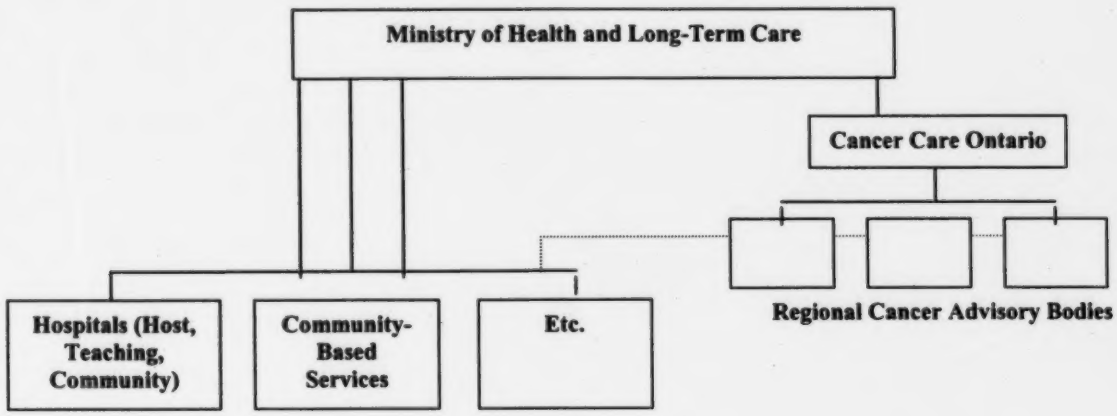
Key Features

- Expand the role of teaching and community hospitals to include governance and management authority for all in- and out-patient cancer care that they provide, and responsibility for linking with other community hospitals, community-based providers and community advisors in each region.

Summary of Committee Observations

- This option would establish local governance and management authority to the local community for all cancer services, and support the integration of in- and out-patient care.
- The challenge is that hospitals lack the regional mandate that is required to advance regional integration and coordination of cancer services among the wide range of providers in the region. It would also result in system destabilisation, since all regional centres would need to be integrated into hospital operations.

Option 4: Strengthen CCO Provincial Role and Role of Regional Bodies



Key Features

- Maintain the governance and management systems that currently exist for cancer services.
- Strengthen the provincial advisory and standards setting role of CCO and the role of regional entities for co-ordinating in- and out-patient cancer care provided by regional centres, hospitals and community-based providers.

Summary of Committee Observations

- This option recognises one organisation that would advise government on all cancer services and be responsible for setting and maintaining standards for all cancer services.
- This option supports a strong regional voice in quality and service coordination.
- The challenge is that CCO must re-focus its efforts on strengthening regional networks and supporting their efforts to meet local needs.

APPENDIX H: ROLES AND RESPONSIBILITIES OF CANCER CARE ONTARIO AND REGIONAL CANCER ADVISORY BODIES

The Committee's report identifies the roles and responsibilities of Cancer Care Ontario and the Regional Cancer Advisory Bodies. These are summarised below.

Role and Responsibilities of Cancer Care Ontario

- Act as principal advisor to the Minister of Health and Long-Term Care on all matters related to the cancer control system and cancer control services.
- Provide comprehensive and strategic advice to the Minister that is objective, and based on an analysis of needs and evidence, and involves the active participation of all stakeholders in building consensus. This advice should focus on the cancer services system and address current and future issues at the provincial, regional and local levels.
- Develop standards and guidelines to support quality cancer care across the full continuum of cancer services.
- Monitor system performance and address problem areas.
- Ensure timely and equitable access to care.
- Ensure the effective use of resources to support the full continuum of cancer services
- Publicly report on system performance.
- Allocate Ministry funds to the regional cancer centres.

Role and Responsibilities of the Regional Cancer Advisory Bodies

- Advise on planning and integrating all regional cancer services.
- Facilitate discussion and decision-making among organisations involved in cancer services in the region so as to improve the quality and integration of these services in the region.
- Monitor compliance with provincial standards and guidelines for in- and out-patient care.
- Evaluate the performance of the cancer services system in the region (e.g., CCO will provide provincial data to the regional bodies to evaluate regional performance).
- Monitor and advise on opportunities to improve clinical and system performance (e.g., wait list monitoring and management, monitoring medical outcomes).
- Understand the money spent within the region on cancer care and advise CCO on regional cancer funding.
- Link funding recommendations to outcome and performance measurement.
- Conduct population health planning to determine the need for cancer services in the region.
- Report to the public and CCO on regional cancer care in such areas as waiting, access, integration of care, and the quality of the patient experience as he or she moves through the system.

APPENDIX I: GUIDELINES AND SUMMARIES DEVELOPED BY CANCER CARE ONTARIO

1. BREAST CANCER

1a. Clinical Practice Guidelines (Published)

- Use of Bisphosphonates in Patients with Bone Metastases from Breast Cancer (Practice Guideline Report No. 1-11)
- Surgical Management of Early Stage Invasive Breast Cancer (Stage I and II) (Practice Guideline Report No. 1-1)
- Breast Irradiation in Women with Early Stage Invasive Breast Cancer Following Breast Conserving Surgery (Practice Guideline Report No. 1-2)
- Epirubicin, as a Single Agent or in Combination, for Metastatic Breast Cancer (Practice Guideline Report No. 1-6)
- Adjuvant Systemic Therapy for Node-Negative Breast Cancer (Practice Guideline Report No. 1-8)
- Management of Ductal Carcinoma In Situ of the Breast (Practice Guideline Report No. 1-10)
- Baseline Staging Tests in Primary Breast Cancer (Practice Guideline No. 1-14)

1b. Guidelines in Progress

- Use of the Taxanes in Stage IV Breast Cancer (Practice Guideline Report No. 1-3)
- The Role of Aromotase Inhibitors in the Treatment of Metastatic Breast Cancer (Practice Guideline Report No. 1-5)
- Local Regional Radiation Therapy Postmastectomy (Practice Guideline Report No. 1-13)

1c. Evidence Summaries

- Use of Trastuzumab (Herceptin) in Metastatic Breast Cancer (Evidence Summary No. 1-15)
- Capecitabine in Stage IV Breast Cancer (Evidence Summary No. 1-16)
- Vinorelbine in Stage IV Breast Cancer (Evidence Summary No. 1-4)

2. GASTROINTESTINAL CANCER

2a. Clinical Practice Guidelines (Published)

- Use of Irinotecan (Camptosar®, CPT-11) Combined with 5-Fluorouracil and Leucovorin (5FU/LV) as First-line Therapy for Metastatic Colorectal Cancer (Practice Guideline Report No. 2-16b)
- Use of Gemcitabine in the Treatment of Advanced Pancreatic Adenocarcinoma (Practice Guideline Report No. 2-10)
- Use of Raltitrexed (Tomudex) in the Management of Metastatic Colorectal Carcinoma (Practice Guideline Report No. 2-17)
- Adjuvant Therapy for Stage II Colon Cancer Following Complete Resection (Practice Guideline Report No. 2-1)

- Adjuvant Therapy for Stage III Colon Cancer Following Complete Resection (Practice Guideline Report No. 2-2)
- Postoperative Adjuvant Radiotherapy and/or Chemotherapy for Resected Stage II or III Rectal Cancer (Practice Guideline Report No. 2-3)
- Use of Irinotecan in the Treatment of Metastatic Colorectal Carcinoma (Practice Guideline Report No. 2-16)

2b. Unpublished Guidelines

- Neoadjuvant or Adjuvant Therapy for Resectable Gastric Cancer (Practice Guideline Report No. 2-14)

2c. Guidelines in Progress

- Systemic Therapy for Unresectable, Recurrent, or Metastatic Gastric Carcinoma (Practice Guideline Report No. 2-5)
- Treatment of Locally Advanced Pancreatic Cancer (Practice Guideline Report No. 2-7)
- Management of Localized Anal Cancer (Practice Guideline Report No. 2-8)
- Follow-up of Patients with "Curatively Resected" Colorectal Cancer (Practice Guideline Report No. 2-9)
- Neoadjuvant or Adjuvant Therapy for Resectable Esophageal Cancer (Practice Guideline Report No. 2-11)
- Combined Modality Radiotherapy and Chemotherapy in the Non-surgical Management of Localized Carcinoma of the Esophagus (Practice Guideline Report No. 2-12)
- The Use of Preoperative Radiotherapy in the Management of Patients with Clinically Resectable Rectal Cancer (Practice Guideline Report No. 2-13)
- Capecitabine in Metastatic Colorectal Cancer (Practice Guideline Report No. 2-15)
- Management of Advanced Colorectal Cancer (Practice Guideline Report No. 2-18)
- Mesorectal Excision for Rectal Cancer (Practice Guideline Report No. 2-20)
- Management of Rectal Cancer (Practice Guideline Report No.2-21)
- Oxaliplatin in Advanced Colorectal Cancer (Practice Guideline Report No. 2-22)

3. GENITOURINARY CANCER

3a. Clinical Practice Guidelines (Published)

- Use of Strontium^{89} in Patients with Endocrine-Refractory Carcinoma of the Prostate Metastatic to Bone (Practice Guideline Report No. 3-6)
- Surveillance Programs for Early Stage Non-Seminomatous Testicular Cancer (Practice Guideline Report No. 3-5)

3b. Unpublished Guidelines

- Use of Adjuvant Chemotherapy Following Cystectomy in Patients with Deep Muscle-Invasive Transitional Cell Carcinoma of the Bladder (Practice Guideline Report No. 3-2-1)
- Use of Neoadjuvant Chemotherapy in Transitional Cell Carcinoma of the Bladder (Practice Guideline Report No. 3-2-2)

3c. Guidelines in Progress

- Role of Total Androgen Blockade in Metastatic Prostate Cancer (Practice Guideline Report No. 3-1)
- Use of alpha Interferon for the Treatment of Patients with Progressing Unresectable Metastic Renal Cell Cancer (Practice Guideline Report No. 3-8-1)
- Use of Interleukin-2 for the Treatment of Patients with Progressing Unresectable Metastic Renal Cell Cancer (Practice Guideline Report No. 3-8-2)
- The Use of Conformal Radiotherapy and the Selection of Radiation Dose in T1 or T2 Prostate Cancer (Practice Guideline Report No. 3-11)
- Use of Chemotherapy in Advanced Unresectable or Metastatic Transitional Cell Carcinoma of the Bladder or Urothelium (Practice Guideline Report No. 3-12)

3d. Evidence Summaries (Published)

- The Use of Brachytherapy in T1 or T2 Prostate Cancer (Evidence Summary No. 3-10)

4. GYNECOLOGICAL CANCER

4a. Clinical Practice Guidelines (Published)

- Use of Topotecan in Pre-treated Recurrent or Relapsed Ovarian Cancer Patients (Practice Guideline Report No. 4-2)

4b. Unpublished Guidelines

- First-line Chemotherapy for Postoperative Patients with Stage II, III or IV Epithelial Ovarian Cancer, Fallopian Tube Cancer, or Primary Peritoneal Cancer (Practice Guideline Report No. 4-1-2)

4c. Guidelines in Progress

- The Role of Chemoradiation in Cervical Cancer (Practice Guideline Report No. 4-5)
- Treatment of Recurrent or Metastatic Endometrial Cancer (Practice Guideline Report No. 4-8)

4d. Unpublished Evidence Summaries

- Chemotherapy for Recurrent Epithelial Ovarian Cancer Previously Treated with Platinum (Evidence Summary No. 4-3)

4e. Evidence Summaries in Progress

- The Role of Prophylactic Oophorectomy (Evidence Summary No. 4-4)
- Screening for Ovarian Cancer (Evidence Summary No. 4-6)

5. HEAD AND NECK CANCER

5a. Clinical Practice Guidelines (Published)

- Neoadjuvant Chemotherapy in Locally Advanced Squamous Cell Carcinoma of the Head and Neck (SCCHN) (excluding nasopharynx) (Practice Guideline Report No. 5-1) [Web Publication only]
- Symptomatic Treatment of Radiation-Induced Xerostomia in Head and Neck Cancer Patients (Practice Guideline Report No. 5-5)
- Concomitant Chemotherapy and Radiotherapy in Squamous Cell Head and Neck Cancer (Excluding Nasopharynx) (Practice Guideline Report No. 5-6a)
- Hyperfractionated Radiotherapy for Locally Advanced Squamous Cell Carcinoma of the Head and Neck (Practice Guideline Report No. 5-6b)
- Accelerated Radiotherapy for Locally Advanced Squamous Cell Carcinoma of the Head and Neck (Practice Guideline Report No. 5-6c)

5b. Guidelines in Progress

- Treatment Indications and Techniques of T3N0 Glottic Cancer (Practice Guideline Report No. 5-2)
- Management of Newly Diagnosed Patients with Advanced Carcinoma of the Nasopharynx (Practice Guideline Report No. 5-7)
- Use of Amifostine in the Radiation Treatment of Head and Neck Cancer (Practice Guideline Report No. 5-8)

5c. Evidence Summaries (Published)

- Optimum Radiation Fractionation for T1 NO Glottic (Vocal Cord) Carcinoma (Evidence Summary No. 5-4)

6. HEMATOLOGICAL CANCER

6a. Clinical Practice Guidelines (Published)

- Fludarabine in Intermediate- and High-Risk Chronic Lymphocytic Leukemia (Practice Guideline Report No. 6-1)
- Drug Therapy for Chronic Myeloid Leukemia (Practice Guideline Report No. 6-3)

6b. Unpublished Guidelines

- Optimal Therapy for Patients Diagnosed with Multiple Myeloma and the Role of High-Dose Chemotherapy and Stem Cell Support (Practice Guideline Report No. 6-6)

6c. Guidelines in Progress

- Treatment with Fludarabine for Patients with Follicular and other Low Grade Non-Hodgkin's Lymphoma and Waldenstrom's Macroglobulinemia (Practice Guideline Report No. 6-2)
- The Role of Bisphosphonates in the Management of Skeletal Complications for Patients with Plasma Cell Myeloma (Practice Guideline Report No. 6-4)

- The Use of G-CSF for Patients Undergoing Bone Marrow and Stem Cell Transplantation (Practice Guideline Report No. 6-5)
- The Use of Chemotherapy and Growth Factors in Older Patients with Newly Diagnosed Aggressive Histology Non-Hodgkin's Lymphoma (Practice Guideline Report No. 6-7)
- Treatment of Essential Thrombocythemia (Practice Guideline Report No. 6-9)
- Interferon in Low-grade Non-Hodgkin's Lymphoma (Practice Guideline Report No. 6-10)
- Surgical Management of Gastric and Intestinal Lymphoma (Practice Guideline Report No. 6-11)
- Role of Erythropoietin in Multiple Myeloma and Non-Hodgkin's Lymphoma (Practice Guideline Report No. 6-12)
- G-CSF/Erythropoietin in Myelodysplasia (Practice Guideline Report No. 6-13)

6d. Evidence Summaries (Published)

- Rituximab in Lymphoma (Evidence Summary No. 6-8)

7. LUNG CANCER

7a. Clinical Practice Guidelines (Published)

- The Role of Single-Agent Docetaxel (Taxotere®) as a Second-Line Treatment for Advanced Non-Small-Cell Lung Cancer (Practice Guideline Report No. 7-7-2)
- Use of Gemcitabine in Non-Small-Cell Lung Cancer (Practice Guideline Report No. 7-8)
- Use of Vinorelbine in Non-Small Cell Lung Cancer (Practice Guideline Report No. 7-5)
- Prophylactic Cranial Irradiation in Small Cell Lung Cancer (Practice Guideline Report No. 7-13-2)
- Postoperative Adjuvant Chemotherapy and/or Radiation Therapy in Stage II or IIIA Completely Resected Non-Small Cell Lung Cancer (Practice Guideline Report Report No. 7-1)
- Chemotherapy in Stage IV (Metastatic) Non-Small Cell Lung Cancer (Practice Guideline Report No. 7-2)
- Altered Fractionation of Radical Radiation Therapy in the Management of Unresectable Non-Small Cell Lung Cancer (Practice Guideline Report No. 7-12)
- The Role of Thoracic Radiotherapy as an Adjunct to Standard Chemotherapy in Limited-Stage Small Cell Lung Cancer (Practice Guideline Report No. 7-13-3)
- Unresected Stage III Non-Small Cell Lung Cancer (Practice Guideline Report No. 7-3)
- Use of Preoperative Chemotherapy with or without Postoperative Radiotherapy in Technically Resectable Stage IIIA Non-Small Cell Lung Cancer (Practice Guideline Report No. 7-4)

7b. Unpublished Guidelines

- The Role of Combination Chemotherapy in the Initial Management of Limited-Stage Small-Cell Lung Cancer (Practice Guideline Report No. 7-13-1)

7c. Guidelines in Progress

- The Role of Paclitaxel (Taxol) in the Treatment of Advanced Non-Small-Cell Lung Cancer (Practice Guideline No. 7-7-1)
- Surgical Management of Malignant Pleural Mesothelioma (Practice Guideline No. 7-14-2)

8. MELANOMA

8a. Clinical Practice Guidelines (Published)

- Systemic Adjuvant Therapy for Patients at High Risk for Recurrent Melanoma (Practice Guideline No. 8-1)

8b. Guidelines in Progress

- Surgical Management of Primary Malignant Melanoma ((Practice Guideline No. 8-2-1)
- Therapeutic Lymph Node Dissection for Malignant Melanoma ((Practice Guideline No. 8-2-2)
- Elective and Sentinel Lymph Node Dissection for Malignant Melanoma (Practice Guideline No. 8-2-3)

8c. Evidence Summaries in Progress

- Biochemotherapy for the Treatment of Metastatic Malignant Melanoma (Evidence Summary No. 8-3)

9. NEURO-ONCOLOGY

9a. Clinical Practice Guidelines (Unpublished)

- Radiotherapy for Newly Diagnosed Malignant Glioma in Adults (Practice Guideline No. 9-3)

9b. Guidelines in Progress

- Treatment of Single Brain Metastases (Practice Guideline No. 9-1)
- Adjuvant Systemic Chemotherapy, Following Surgery and External Beam Radiotherapy, for Adults with Newly Diagnosed Malignant Glioma (Practice Guideline No. 9-2)
- Venous Thromboembolism in Malignant Glioma: Incidence, Prophylaxis and Treatment (Practice Guideline No. 9-6)

9c. Evidence Summaries (in Progress)

- Use of Temozolomide in the Treatment of Newly Diagnosed or Recurrent Malignant Glioma (Evidence Summary No. 9-5)
- Gliadel Wafers in the Treatment of Malignant Glioma (Evidence Summary No. 9-7)
- Surgery for Adult Patients with Suspected Malignant Glioma (Evidence Summary No. 9-8)

- Malignant Extradural Spinal Cord Compression: Diagnosis and Management (Evidence Summary No. 9-9)

10. PEDIATRIC CANCER

10a. Clinical Practice Guidelines
None at this time

11. SARCOMA

11a. Clinical Practice Guidelines (Published)
- Doxorubicin-based Chemotherapy for the Palliative Treatment of Adult Patients with Locally Advanced or Metastatic Soft Tissue Sarcoma (Practice Guideline Report No. 11-1)

11b. Unpublished Guidelines
- Adjuvant Chemotherapy Following Complete Resection of Soft Tissue Sarcoma in Adults (Practice Guideline Report No. 11-2)

11c. Guidelines in Progress
- Localized Treatment in Extremity Soft Tissue Sarcoma (Practice Guideline Report No. 11-3)
- Ifosfamide-based Combination Chemotherapy in Advanced Soft Tissue Sarcoma (Practice Guideline Report No. 11-4)
- Use of High-dose Chemotherapy in Advanced Soft Tissue Sarcoma (Practice Guideline Report No. 11-5)
- Appropriate Analogues, Doses, and Schedules for Treatment of Locally Advanced or Metastatic Adult Soft Tissue Sarcoma with Anthracyclines and/or Oxazaphosphorines (Practice Guideline Report No. 11-6)

12. SUPPORTIVE CARE

12a. Clinical Practice Guidelines (in Progress)
- Treatment of lymphedema related to breast cancer (Practice Guideline Report No. 13-1)
- Radiotherapy fractionation for the palliation of uncomplicated painful bone metastases (Practice Guideline Report No. 13-2)
- Assessing psychosocial distress in cancer patients (Practice Guideline Report No. 13-3)

13. SYSTEMIC TREATMENT

13a. Clinical Practice Guidelines (Published)
- Use of 5-HT3 Receptor-antagonists in Patients Receiving Moderately or Highly Emetogenic Chemotherapy (Practice Guideline Report No.12-3)

- Use of Dexrazoxane as a Cardioprotectant in Patients Receiving Doxorubicin or Epirubicin Chemotherapy for the Treatment of Cancer (Practice Guideline Report No. 12-5)
- Erythropoietin in the Management of Cancer Patients with Non-hematologic Malignancies Receiving Chemotherapy (Practice Guideline Report No. 12-1)
- Use of Granulocyte Colony-Stimulating Factor (G-CSF) in Patients Receiving Myelosuppressive Chemotherapy for the Treatment of Cancer (Practice Guideline Report No. 12-2)
- Use of Amifostine to Ameliorate the Toxic Effects of Chemotherapy in the Treatment of Cancer (Practice Guideline Report No. 12-6).

13b. Guidelines in Progress

- Use of Octreotide in Cancer Patients (Practice Guideline Report No. 12-7)
- Liposomal Anthracyclines in the Management of HIV-positive Kaposi's Sarcoma (Practice Guideline Report No. 12-8)

APPENDIX J: MINISTRY FUNDING TO CANCER CARE ONTARIO

MINISTRY FUNDING TO CANCER CARE ONTARIO FOR THE DELIVERY OF PROGRAMS AND SERVICES TO CANCER PATIENTS

Fiscal Year	Opening Base (million)	New Funding (millions)	Percent Increase Opening Base to Opening Base	Total Funding (Base + 1x)	Percent Increase Total Funding Year over Year)	Programs and Services Funded in that Year
94/95	$127.753	$5.220	0%	$132.973	0%	Mix of base ($3.1m) and onetime ($2.1m) funding for Toronto Sunnybrook expansion and for depreciation on radiation treatment equipment
95/96	$130.861	$4.330	2.4%	$135.191	1.7%	Onetime for new drugs (Taxol) and new program in treatment guidelines
96/97	$130.417	$8.599	-0.3%	$139.016	2.8%	Onetime for treatment services (drugs) and program in cancer information service
97/98	$130.417	$11.900	0.0%	$142.317	2.4%	Base for treatment services (drugs) new program in surgical oncology and guidelines development and new program in cervical cancer screening
98/99	$142.317	$16.237	9.1%	$158.554	11.4%	Base for radiation therapy ($4.6m) systemic therapy ($1.5m) prostate brachytherapy ($1.5m) prevention, supportive care, CCORs ($2.6m) new drugs ($6.0m)
99/00	$158.554	$18.469	11.4%	$177.023	11.6%	Base for radiation treatment ($11.1) new drugs ($7.0m) new physicists training program
00/01	$177.023	$34.884	11.6%	$211.907	19.7%	Base for systemic therapy ($9.7m) new drugs ($17.6m) radiation treatment ($1.5m per case funding) other programs and administration ($6.0m)

Note:
Over the past 7 years (beginning 1994/95 to present) the Ministry has provided $84.2 million in funding to CCO or about $12 million annually. In percentage terms, this funding is an average annual increase of 9.4% year-over-year.

In 1995/96 and 1996/97, hospitals received a 5% and 6% reduction to their operating base. These reductions were not applied to CCO.

Since 1998/99, CCO has received a 35% increase in funding to their radiation treatment program going from a base of $44.9m in 98/99 to $61.9m in 00/01.

MINISTRY INVESTMENTS IN CANCER CAPITAL EXPANSION, REFERRAL OF CANCER PATIENTS AND FUNDING OF CANCER TREATMENT EQUIPMENT		
Fiscal Year	**Ministry Funding**	**Cancer Service**
99/00	$186.2 million	Construction of five new cancer centres and to expand five of the existing eight cancer centres
99/00	$15.5 million growing to $20.9 million by 2002/2003	Expand radiation therapy training program at Michener Institute, add new training program at CCO for medical physicists, enhance international recruitment efforts for radiation professionals
99/00 and 00/01	$46.2 million	Referral of 2,400 breast and prostate cancer patients the United States (70%) and to other Ontario cancer centres (30%) primarily Thunder Bay
00/01	$20 million	Ministry funding at 100% for the replacement of radiation treatment machines